Understanding posttraumatic stress symptoms in carers of people with psychosis A cross-sectional study

Kingston, Cara

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Cara Kingston

Institute of Psychiatry, King's College London

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MAIN THESIS

Understanding posttraumatic stress symptoms in carers of people with psychosis: A cross-sectional study

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Cara Kingston

Institute of Psychiatry, King's College London

Supervised by

Dr. Juliana Onwumere

Prof. Elizabeth Kuipers

Dr. Nadine Keen

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Abstract

Background: Many service users with psychosis will live with and/or maintain regular contact with informal carers. Findings from a small number of studies suggest that a significant number of carers of people with psychosis experience posttraumatic stress symptoms (Barton & Jackson, 2008; Loughland et al. 2009; Boye & Malt, 2002). However, it is unclear how these symptoms relate to a broader range of carer characteristics. The application of a stress and coping framework, including components from the cognitive model of PTSD (Ehlers & Clark, 2000) may help us to understand the relationships between posttraumatic stress symptoms and well-being in carers, and in turn help to shape interventions for both carers and service users.

Aims: In a sample of carers of people with psychosis the study aimed to explore posttraumatic stress symptoms, including intrusive imagery, and to examine the relationship between posttraumatic stress symptoms, well-being and caregiving experiences.

Methods: Thirty-two carers of people with psychosis completed self-report questionnaires and short interviews assessing posttraumatic stress symptoms, negative caregiving appraisals, appraisals of trauma, avoidant coping style, social support, expressed emotion, physical health and sleep quality.

Results: Almost half (n = 15; 44%) of the participants reported symptoms of posttraumatic stress. Posttraumatic stress symptoms were associated with negative appraisals of caregiving, negative appraisals of trauma, greater levels of avoidant coping, and lower reported physical health. Associations between posttraumatic stress symptoms and social support, expression emotion and sleep quality, were not found. Negative intrusive images were identified in 35% (n = 11) of carers. Images were appraised as vivid and moderately to extremely distressing; and elicited strongly held negative beliefs about the self, others or the world.

Conclusions: This study supports existing research to suggest that carers of people with psychosis can experience posttraumatic stress symptoms related to their caring role. It also lends support for the application of a stress and coping framework to understand relationships between posttraumatic stress symptoms and carer characteristics. Conclusions are limited by a relatively small sample and cross-sectional design. Future research is needed to assess causal relationships and the role of other factors implicated within theoretical models of stress and coping. The findings indicate that posttraumatic stress symptoms should be considered when designing and implementing interventions to meet carer needs and improve outcomes for both carers and service users.

1 Introduction

This section begins with a description of schizophrenia and related disorders, followed by a discussion on caregiving in psychosis and the research findings detailing the impact of traumatic life experiences on carers. Psychological models of stress and coping are reviewed to provide a framework for understanding possible relationships between posttraumatic stress symptoms and caregiving variables including appraisals, coping style, social support, expressed emotion and physical health. The gaps in the literature are highlighted. The chapter concludes with the study aims and hypotheses.

1.1 Understanding Psychosis

1.1.1 Schizophrenia and psychosis

Schizophrenia and related disorders (e.g., schizoaffective disorder, schizophreniform disorder, delusional disorder) are typically characterised by disruption to cognitive, emotional and social processes, and can include hallucinations, delusions, disturbances in thinking, and reduced social functioning as their main symptom groups (DSM-IV-TR; American Psychiatric Association, 2000). "Psychosis" is a term used to describe the presence of the positive symptoms of schizophrenia. It is often used interchangeably with schizophrenia and favoured by researchers whilst debate continues about the validity of "schizophrenia" (Bentall, 2004). This approach will also be adopted in the current study.

Schizophrenia can be a persistent and debilitating psychiatric disorder (American Psychiatric Association, 2000) and is ranked in the top 25 grand challenges in global mental health in terms of priorities for research and treatment (Collins et al., 2011). The lifetime prevalence of schizophrenia is between 1.6 and 12.1 per 1,000 people (Saha, Chant, Welham, & McGrath, 2005). Recent figures estimate that only 14% to 20% of

individuals with schizophrenia will achieve full clinical and social recovery (Rosen & Garety, 2005; Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004). They experience high levels of social exclusion (Tarrier, Khan, Cater, & Picken, 2007) with approximately 80% of working age adults registered as unemployed (Marwaha & Johnson, 2004). In addition to impaired social functioning, individuals with schizophrenia experience episodic and recurrent psychiatric relapses (Robinson et al., 1999).

Schizophrenia is associated with a number of other conditions including posttraumatic stress disorder and substance misuse, as well as a greater risk of suicide. Several studies suggest that the diagnosis and experience of psychosis can be a devastating and traumatic event with reported rates of PTSD at 50% (Shaw, McFarlane, Bookless, & Air, 2002; Frame & Morrison, 2001). Rates of substance misuse are much higher in people with psychosis than for the general population. A widely cited epidemiological study (Regier et al., 1990) identified 47% of participants with a diagnosis of schizophrenia had a lifetime prevalence of some form of substance use disorder. In the United Kingdom (UK), estimates from treatment setting surveys suggest past year prevalence rates of around 25% (Graham et al., 2003; Weaver et al., 2001). A recent meta-analysis of suicide risk in people with schizophrenia estimates that 4.9% of people with schizophrenia will commit suicide during their lifetime, with higher rates during the early illness phase (Palmer, Pankratz, & Bostwick, 2005).

Core interventions in the treatment of schizophrenia in adults are outlined within the National Institute for Health and Clinical Excellence (NICE) clinical guideline (2009, update). In summary, the recommended evidence-based psychological interventions to be offered to all service users are: Cognitive Behaviour Therapy (CBT) and Family

Intervention (FI) for service users who live with or are in close contact with families. The guidelines also make pharmacological recommendations that include oral antipsychotic medication for people with newly diagnosed schizophrenia; and clozapine, an atypical antipsychotic, for people with treatment resistant schizophrenia. Similar treatment guidelines can be found in the USA (PORT; Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2010)

1.1.2 Caregiving in psychosis

Policy changes concerning the care of individuals with severe mental illness, specifically the shift from institutional to greater community based care (e.g., home treatment or crisis resolution teams) and a greater emphasis on reducing the length of inpatient admissions, has required informal carers (usually relatives) to become increasingly involved in the day-to-day care of people with serious mental health problems (Cuijpers, 1999; Kuipers, Onwumere, & Bebbington, 2010; Milliken & Northcott, 2003; Awad & Vorugant, 2008). Studies have shown that 50% to 90% of individuals with a serious mental illness live with their families (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003). Informal caregivers provide an important role supporting individuals with psychosis, facilitating recovery and responding to areas of unmet needs (Fleury, Grenier, Caron, & Lesage, 2008; Szmukler et al., 2003; Tryssenaar & Tremblay, 2002). It is now well recognised that carers make a positive contribution to an individual's recovery (NICE, 2009) and are a resource in the management of psychosis (Kuipers & Bebbington, 1985).

1.1.3 Definition of caregiving in psychosis

There is no uniform definition of a "carer". Although not confined to mental health carers, the Princess Royal Trust for Carers defines a carer as "someone who, without

payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help" (www.carers.org). The NICE clinical guidelines for schizophrenia (NICE, 2009) use the term carer to apply to "everyone who has regular close contact with the person with schizophrenia, including advocates, friends or family members, although some family members may choose not to be carers" (p. 5-6). However, the debate surrounding how carers define themselves (e.g., carer, parent or "supporter") is not thought to affect the impact that the role has on an individual (Kuipers, et al., 2010). In the context of psychosis, Kuipers and Bebbington (2005) described the caring role as "an inherently unequal role; the person doing the caring has more responsibility, and has more to do than the person being cared for, who is to some extent dependent" (p. 217).

1.1.4 Impact of caregiving

Recent evidence demonstrates that caregiving can be associated with feelings of satisfaction, personal growth, and improved relations between caregiver and patient (Chen & Greenberg, 2004; Greenberg, Seltzer, & Judge, 2000; Veltman, Cameron, & Stewart, 2002). However, research spanning six decades confirms that the caregiver role can also exert a negative impact on their psychological and physical well-being (Treudley, 1946; Fadden, Bebbington & Kuipers, 1987; Schene, Wijngaarden, & Koeter, 1998). Carers of people with psychosis often experience high levels of distress (Kuipers & Bebbington, 2005; Roick et al., 2007) with at least 30% to 40% reporting clinical levels of depression (Kuipers & Raune, 2000; Dyck, Short, & Vitaliano, 1999; Lowenstein, Butler, & Ashcroft, 2010). Evidence suggests a higher risk of distress in family members of individuals with first episode psychosis (Martens & Addington, 2001) and those who have been recently been admitted to a psychiatric facility (Boye & Malt, 2002), and that distress can be enduring (Brown & Birtwistle, 1998). Carers are

also known to experience high levels of loss that are equivalent to levels reported in physical bereavement (Patterson, Birchwood, & Cochrane, 2005; Magliano, Marasco, Fiorillo, Guarneri, & Maj, 2002). The stigma and shame associated with mental ill health can lead to a significant reduction in the social networks and support for carers (Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005; Gutierrez-Malondado, Caqueo-Urizar, & Kavanagh, 2005; Chambers, Ryan, & Connor, 2001). This will often leave carers feeling isolated particularly in comparison to carers of people with other long term, complex conditions such brain injury (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). Further, it is not uncommon for carers to report feelings of fear about their relative's behaviour and anxiety about what the future holds (Barker, Lavender, & Morant, 2001). Carers of people with psychosis also report high levels of burnout (e.g., emotional exhaustion) not dissimilar to levels reported by professional psychiatric personnel (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006). Caregiving burden has also been associated with physical health problems (Perlick, Hohenstein, Clarkin, Kaczynsk, & Rosenheck, 2005) and sleep disruption (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). Recently, posttraumatic stress symptoms have been identified in carers of people with psychosis (Barton & Jackson, 2008; Loughland et al., 2009; Boye & Malt, 2002).

1.2 Posttraumatic Stress Symptoms in Carers

1.2.1 Posttraumatic stress symptoms

Posttraumatic stress symptoms are varied and can include intrusive re-experiencing aspects of the traumatic event, avoidance of reminders of the event or a numbing of emotions, and hypervigilance or increased physiological arousal. In order to meet the DSM-IV-TR (American Psychiatric Association, 2000) criteria for Posttraumatic Stress Disorder (PTSD), an identifiable stressor that is potentially life-threatening needs to be

defined and the content of the symptoms should refer the stressor (Breslau, Chase, & Anthony, 2002). According to DSM-IV-TR, an individual must have experienced an event in which both of the following are present: 1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatening death or serious injury, or a threat to the physical integrity of self or others; 2) the person's response involved intense fear, helplessness, or horror (Criteria A). Posttraumatic stress symptoms on their own, without being connected to a stressor, would not meet criteria for a PTSD diagnosis and instead may be indicative of other emotional disorders, such as anxiety or depression, which can overlap with PTSD (Bleich, Koslowsky, Doley, & Lerer, 1997).

Although the DSM-IV indicates that significant others can also be significantly affected by a traumatic event that they witness or learn of, PTSD diagnostic criterion has been criticised for being too restrictive (Power & Dalgleish, 1997) and for failing to acknowledge the psychological impact of interpersonal trauma such as childhood abuse (Allen, 2001) or psychosis (Shaw, McFarlane, & Bookless, 1997). If we consider caregiving relationships, it is possible that the current operational definitions of PTSD in DSM-IV will also fail to capture potentially traumatic stressors that are commonly experienced by carers of people with psychosis. It could be argued, for example, that non-life threatening, objective events such as police involvement in the pathway to treatment, compulsory detainment under the Mental Health Act (1983), and psychotic behaviour in a loved relative, may be related to posttraumatic stress symptoms observed in people who care for someone with psychosis. Genuine traumatic symptoms may be missed and theoretical developments restricted, if research adheres rigidly to current criterion (Jackson, Knott, Skeate, & Birchwood, 2004). There are several reports of people exhibiting full PTSD symptoms, without the direct experience of acute

precipitating trauma (Ravin & Boal, 1989; Scott & Stradling, 1994) that are similar to those following more catastrophic trauma (Spurrell & McFarlane, 1995), but due to cumulative stressors or vicarious traumatisation. These findings provide some support for the validity of PTSD as a possible consequence of caregiving in psychosis.

In line with Ehlers and Clark's (2000) widely cited cognitive model, carers may appraise their experiences as stressful and even life-threatening (e.g., believing there is risk of death when threatened by person with psychosis). It seems important therefore to ensure that current research approaches avoid being unduly limited by over-simplified models of "traumatic event causes PTSD" and to consider the role of cognitive mediation (Jackson et al., 2004). It is now recognised that there are a range of event characteristics which contribute to the experience of trauma including: duration of impact, unexpectedness, presence of threat after the event, ratio of loss versus available resources, potential for prolonged alteration of post-disaster environment and perceptions of control (Foy, Sipprelle, Rueger, & Carroll, 1984; Lyons, 1991).

Although the importance of identifying posttraumatic stress symptoms that cause significant distress and impairment in functioning is evident, care also needs to be taken not to medicalise normal responses to traumatic and stressful life events. This may be of particular concern when identifying posttraumatic stress symptoms that do not necessarily fulfil the strict definition of PTSD. In relation to the current study, given its emphasis on posttraumatic stress symptoms, there is a risk that it may involve the medicalisation of distress by identifying or framing normal experiences of caregiving and experiences significantly influenced by social factors as mental ill health and by implication, something in need of treatment. However, while taking care not to medicalise, there is insufficient evidence to suggest that investigations into

posttraumatic stress symptoms and the potential psychosocial interventions aimed at ameliorating these symptoms amongst carers of people with psychosis are misplaced.

1.2.2 Posttraumatic stress symptoms in carers

In the last decade, posttraumatic stress symptoms have been found in carers of people with mental health problems. For instance, spouses and other family carers having daily contact with patients with dementia have been found to experience moderate to high levels of intrusions and avoidance (Ulstein, Wyller, & Engedal, 2008). PTSD symptoms have also been documented in informal caregivers of stroke survivors (Carek, Norman, & Barton, 2010) and other life-threatening illnesses (e.g., Noble & Schenk, 2008). Parents of children with life-threatening illnesses or severe injury also report trauma symptoms (e.g., Stoppelbein & Greening, 2007; Alderfer, Cnaan, Annunziato, & Kazak, 2005; Kazak et al., 2004; Manne et al., 2004; Hall et al., 2006). PTSD symptoms have also been found in formal carers (i.e. paid staff), for instance, psychiatric nursing staff (Cladwell, 1992; Wildgoose, Briscoe, & Lloyd, 2003), dementia healthcare workers (Scott, Ryan, James & Mitchell, 2011) and emergency worker staff (Laposa & Alden, 2003).

1.2.3 Posttraumatic stress symptoms in carers of people with psychosis

Research indicates that the conditions surrounding the onset of psychosis can also often be medically aversive and distressing for both patients and carers (Schene et al., 1998; Lauber et al., 2003). Carers can interpret the risk of patient suicide and illness related stigma (Struening et al., 2001) as potentially threatening and some carers may become the focus of paranoid ideas or delusions, which result in their relative threatening, or causing them, actual bodily harm (Ferriter & Hubband, 2003). As part of their role, carers of people with psychosis report exposure to a broad range of aggressive

behaviours, including verbal, physical, self-directed and sexual aggression (Ferriter & Hubband, 2003; Loughland et al., 2009; Vaddadi, Soosni, Gilleard, & Adlard, 1997). Substance use among individuals with schizophrenia is frequent (Green, Drake, Brunette, & Noordsy, 2007) and often associated with verbal or physical aggression towards caregivers (Vaddadi et al., 1997). In a qualitative study of couples caring for adult children with psychosis, results indicated that some carers described feeling "frightened for our lives" (Wane, Larkin, Earl-Gray, & Smith, 2009). The authors commented that many of the accounts were reminiscent of trauma narratives and emotions of fear, frustration and helplessness were still evident despite many years of service involvement and caring. Furthermore, there is now substantial evidence of posttraumatic stress symptoms in individuals with psychosis (e.g., Shaw et al., 2002; Frame & Morrison, 2001) therefore carers may be at risk of secondary or vicarious traumatization as seen, for example, in partners of veterans (Galovski & Lyons, 2004). As indicated by the DSM-IV, significant others can be significantly affected by a traumatic event that they witness or learn of.

Boye and Malt (2002) found that relatives of acutely admitted psychotic patients experienced strong acute and persistent stress responses, similar to those described in those exposed to severe or life threatening illness. More recently, Barton and Jackson (2008) found that in a sample of people caring for someone with recent onset psychosis, more than one-third (35.1%) reported symptoms of traumatic stress. Similarly, in a sample of carer-relatives, Loughland et al. (2009) found that over two thirds (77%) reported experiencing moderate-severe aggression and approximately half of these carer-relatives reported significant posttraumatic stress symptoms. In this study, a significant portion of carers also reported extreme concern that aggression would occur again in the future (21.7%) and reported fearing for their lives as a result of the

aggression (23.6%). Preliminary evidence from these studies also suggested that posttraumatic stress symptoms were associated with greater distress in carers (Boye & Malt, 2002; Loughland et al., 2009). These studies did not include an examination of the association between posttraumatic stress symptoms and a broader range of carer characteristics (e.g., negative appraisals of caregiving and expressed emotion). Therefore, it is as yet unknown whether posttraumatic stress symptoms are linked to the caregiving relationship.

The impact posttraumatic stress symptoms may have on current psychological interventions with carers is also currently unknown. Family intervention in psychosis has shown some improvement in carer "burden" (Cuijpers, 1999) however most improvement has been in reducing service user relapse and readmission (NICE, 2009; Pharoah, Mari, Rathbone, & Wong, 2010; Bird et al., 2010). In comparison, only a few studies have demonstrated a positive impact on carer well-being (e.g., Berglund, Vahlne, & Edman, 2003). It is possible that avoidance symptoms may inhibit some carers from participating in effective family problem solving and a high level of intrusions may prevent some carers from benefiting optimally from these interventions.

1.3 Psychological Models of Stress and Coping

1.3.1 Stress, appraisal, coping framework

Previous studies have adopted a stress, appraisal, and coping (SAC) framework (Lazarus & Folkman, 1984) to understand caregiving experiences such as distress (e.g., Szmukler et al., 1996; Mackay & Pakenham, 2011). The SAC framework defines psychological stress as, "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 21). A simple model of the SAC

framework is illustrated in Figure 1. In accordance with the SAC framework (Lazarus & Folkman, 1984), it is proposed that carers make appraisals (i.e., evaluative judgements) about the impact of the illness and these appraisals then interact with coping abilities to determine their psychological well-being and distress (Szmukler et al., 1996). Other factors, such as social support, can modify this appraisal and coping ability and potentially modify outcome (Szmukler et al., 1996). Adjustment to caregiving and the service user's illness is therefore seen to be determined by three cognitive, behavioural and interpersonal processes: cognitive appraisals, coping strategies (e.g., avoidance) and coping resources (e.g., social support) (Mackay & Packenham, 2011). In particular, events related to the caregiving role that are appraised as threatening, uncontrollable and/or limiting opportunities for personal growth, are seen to have a negative influence on adjustment because these appraisals will generate stress which may exceed available coping skills and resources (Mackay & Peckenham, 2011). Szmuckler et al. (1996) found that carers of people with psychosis made negative appraisals of caregiving, specifically in relation to: the service user's difficult behaviours, negative symptoms and dependence upon them; stigma and loss associated with the illness; problems with services; and the effects of the illness on the family.

Figure 1. A 'stress-coping' model of caregiving (from Smuckler et al., 1996)

Figure removed due to copyright restrictions

The SAC framework (Lazarus & Folkman, 1984) suggests that it is the appraisals that caregivers make about caregiving, not their objective circumstances, that are associated with their psychological well-being. Consistent with this, negative caregiving appraisals have been associated with high levels of psychological distress in caregivers (Onwumere et al., 2008; Szmukler et al., 1996; Addington, Coldham, Jones, & Addington, 2003; Martens & Addington, 2001; Tucker, Barker, & Gregoire, 1998; Harvey, Burns, Fahy, Manley, & Tattan, 2001). In one study, carer psychological well-being was related to their appraisals about stigma, problems with family, patient dependency and their difficult behaviours, and feelings of loss (Martens & Addington, 2001). Barrowclough and Parle (1997) found that appraisals of symptom threat and symptom control were related to psychological distress in relatives of people with

psychosis. Onwumere et al. (2008) found that carers of people with psychosis reported greater distress when they perceived the illness as having severe consequences for themselves and the patient, and when they perceived it to be long-term.

1.3.2 A cognitive model of PTSD

Ehlers and Clark (2000), in their cognitive model of PTSD, propose that PTSD becomes persistent in individuals whose processing of the event leads to a sense of serious current threat as a result of disturbances in autobiographical memory and idiosyncratic negative appraisals of the traumatic event and/or its sequelae. The threat can be either internal (e.g., a threat to one's core view of oneself as a capable and/or acceptable person who will be able to achieve life's important goals) or external (e.g., the world is a dangerous place, people are dangerous). The sense of current threat is accompanied by intrusions, arousal, and strong emotions such as anxiety, anger, shame, or sadness. These negative appraisals also lead to a series of dysfunctional cognitive and behavioural responses that have the short-term aim of reducing distress, but have the long-term consequence of preventing cognitive change and therefore maintain the disorder.

As outlined above, Ehlers and Clark (2000), in their cognitive model of PTSD, place great importance on the role of excessively negative appraisals of traumatic events and/or their sequelae, in the onset and maintenance of the disorder. Three types of negative trauma event appraisals have been distinguished by Foa, Ehlers, Clark, Tollin, and Orsillo (1999) including, negative cognitions about the self, negative cognitions about the world, and self-blame. These have been found to be associated with PTSD symptom severity in cross-sectional (e.g., Agar, Kennedy, & King, 2006; Laposa & Alden, 2003) and prospective analyses (e.g., Ehring, Ehlers, & Glucksman, 2008;

O'Donnell, Elliot, Wolfgang, & Creamer, 2007). Consistent with the PTSD model, negative cognitions about the self and world, and self-blame have been found to correlate with the severity of posttraumatic stress symptoms experienced by informal carers of stroke survivors (Carek et al., 2010) and by parents of children with a serious illness (Horsch, McManus, & Kennedy, 2012). Furthermore, self-blame, conceptualised as a coping strategy has been associated with posttraumatic stress symptoms in informal carers of patients with a life-threatening illness (Noble & Schenk, 2008). In carers of people with psychosis, coping through self-blame has been associated with higher levels of distress (Fortune, Smith, & Garvey, 2005). Barrowclough, Tarrier, and Johnson (1996) also found that those relatives of people with psychosis who made self-blaming attributions experienced higher levels of distress than those who did not.

1.3.3 Appraisals and posttraumatic stress symptoms in carers of people with psychosis

To date, the author is of only aware of one study in carers of people with psychosis that has attempted to examine the association between the cognitive processes and coping strategies, implicated by models of stress and coping, and posttraumatic stress symptoms in carers of people with psychosis (i.e., negative appraisals of caregiving, negative appraisals of trauma, avoidant coping, and social support). Loughland et al. (2009) looked at the association between posttraumatic stress symptoms, coping strategies and appraisals of threat and blame. The study measured cognitive appraisals (e.g., attributions of blame, concern regarding future aggression, and perceived life threat) using three questions adapted from a trauma interview (Brewin, Andrews, & Rose, 2000). The authors did not find an association between these appraisals and posttraumatic stress symptoms, nor did they find that the type of coping strategies differed between low and high trauma participant groups. However, the authors cite several limitations to their study including the possibility of a biased sample and the

relevance of the perceived threat question to the sample. It remains unclear whether relationships exist between posttraumatic stress symptoms and appraisals of caregiving experiences in carers of people with psychosis, and whether any existing relationships can be understood within current models of stress and coping, such as the SAC framework (Lazarus & Folkman, 1984) or the cognitive model of PTSD (Ehlers & Clark, 2000).

1.4 Coping and Social Support

1.4.1 Avoidant coping strategies

The cognitive model of PTSD (Ehlers & Clark, 2000) also highlights an important role for coping mechanisms and posits that negative appraisals can prompt less adaptive coping styles that are based strongly on avoidance. According to this model, avoidance may be used as a defence against distress caused by intrusive phenomena associated with PTSD. Avoidance may create short-term reductions in distress, but it is ultimately counterproductive as it is thought to play a role in maintaining intrusions (Ehlers & Steil, 1995). Consistent with this model, avoidant coping has been positively associated with PTSD symptoms among war veterans (e.g., Sutker, Davis, Uddo, & Ditta, 1995), motor vehicle accident survivors (e.g., Bryant & Harvey, 1995), and victims of sexual and nonsexual assault (Dunmore, Clark, & Ehlers, 1999; Valentiner, Foa, Riggs, & Gershuny, 1996).

The SAC framework (Lazarus & Folkman, 1984) defines coping as the person's constantly changing cognitive and behavioural efforts to manage (i.e., master, reduce, or tolerate) an encounter appraised as stressful (Provencher, Fournier, Perreault, & Vezina, 2000). Within this framework, avoidant coping tends to be used when appraisals of threat related to stressors exceeds coping resources (Raune, Kuipers, & Bebbington,

2004). In psychosis, avoidant coping may be useful for problems that resolve naturally, but not with worsening or more enduring problems (Kuipers et al., 2010). Active and proactive strategies are believed to be more effective at reducing impact on levels of carer burden, even in the early stages of illness, whereas avoidant coping has been found to be strongly associated with burden, distress and high expressed emotion (Scazufca & Kuipers, 1999; Raune et al., 2004; Onwumere, Kuipers, & Bebbington, 2011; Mackay & Pakenham, 2011; Magliano et al., 2000).

Maladaptive coping has been associated with severity of PTSD symptoms in informal carers following life-threatening illness, including the use of self-distraction, denial, behavioural disengagement and self-blame (Noble & Schenk, 2008). Loughland et al. (2009) found that carers of people with psychosis reporting higher levels of posttraumatic stress symptoms used coping strategies with more frequency when confronted with aggression, compared with carers with lower levels of posttraumatic stress symptoms. However, there were no differences between the two groups of carers on the type of coping strategies utilised; both groups tended to use more positive (e.g., seeking social support, problem-focused strategies) than negative (e.g., self-isolation, self-blame) coping strategies when aggression occurred. Given the limited number of studies, further research is needed to clarify the relationship between avoidant coping strategies and posttraumatic stress symptoms in carers of people with psychosis.

1.4.2 Social support

The SAC framework (Lazarus & Folkman, 1984) describes social support as a resource that can modify the influence of appraisals of caregiving experience and coping ability and potentially modify outcome in terms of carer distress (Joyce et al., 2003). Joyce et al. (2003) studied carers of people with psychosis and found that coping was associated

with social support and concluded that effective coping in caregivers of people with psychosis may improve with support from confidantes. Social support has also been associated with better health and higher life satisfaction in carers of people with psychosis (Mackay & Peckenham, 2011). However, carers' social networks can be negatively affected by their role and can diminish over time (Greenblatt, Bercera, & Serafetinides, 1982; Anderson, Hogarty, Bayer, & Needleman, 1984). Magliano et al. (2005) found that carer burden was significantly higher among relatives caring for someone with schizophrenia who reported lower support from their social network and professionals.

It is possible that carers who experience posttraumatic stress symptoms may be vulnerable to experiencing reduced social networks. Social support has been shown to be negatively correlated with the development and maintenance of PTSD (e.g., Brewin, Andrews, & Valentine, 2000). We know from the cognitive model of PTSD that people with persistent PTSD are likely to avoid social activities (Ehlers & Clark, 2000). The "here and now" quality of intrusions may be interpreted as a sign by the individual that they are unable to relate to other people or that their relationships with others have permanently changed for the worse (Ehlers & Clark, 2000). Consistent with this, Horsch et al. (2012) found that social support was negatively associated with posttraumatic stress symptoms in mothers of children with type 1 diabetes.

1.5 Expressed Emotion

The family environment of a person with psychosis has been extensively measured using the concept of expressed emotion (EE). The methodology associated with this concept was initially used to investigate and describe the effects of different social environments after individuals with psychosis returned home from inpatient admissions

(Brown & Rutter, 1996). In EE, the emotional aspects of close relationships are measured using prosodic variables, pitch, tone and emphasis (Kuipers, 1979). EE measures key aspects of interpersonal relationships including criticism, hostility, warmth, positive comments, and emotional over-involvement (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). Carers can be classified as being either high or low on EE. Carers described as high in EE typically express above threshold levels of critical, hostile and/or emotionally over-involved behaviours towards the individual with psychosis. Conversely, those below the threshold are rated as low EE. High EE in carers has been found to be a robust predictor of relapse in individuals with psychosis (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). In a meta-analysis of 25 worldwide studies of EE and patient outcomes, individuals returning to live with high EE families after a hospital admission had a 50% relapse rate nine months later, compared with 22% in individuals returning to low EE families (Bebbington & Kuipers, 1994). High EE is also predictive of outcome in other health and psychiatric conditions (see Wearden et al., 2000, for a review), such as diabetes (Weardon, Ward, Barrowclough, Tarrier, & Davies, 2006) and bipolar affective disorder (Kim & Miklowitz, 2004). Given the level of involvement of carers in the care and treatment of service users with psychosis and the importance of EE to patient outcomes, EE remains an important concept to measure and understand.

1.5.1 Factors associated with expressed emotion

In order to facilitate a better understanding of EE, several factors have been investigated in relation to EE. The evidence suggests that relatives with high levels of criticism are more likely to attribute to patients more control over their symptoms and problems, and hold them responsible for their difficulties (Barrowclough & Hooley, 2003). Research has found that high critical comment carers make fewer attributions regarding their own

role in the illness (Barrowclough, Johnston, & Tarrier, 1994; Tarrier et al., 2002) whereas relatives with high levels of emotional over-involvement (EOI) tend to attribute greater levels of blame and control to themselves (Peterson & Docherty, 2004). EOI has been associated with feelings of loss (Patterson et al., 2005), self-blame and guilt about being responsible for the individual's illness (Leff & Vaughn, 1985; Bentsen et al., 1998; Peterson & Docherty, 2004). Disagreements between carer and service users about illness controllability have been associated with greater distress, depression, and lower self-esteem in carers (Kuipers et al., 2007) and such disagreements tend to be observed more in high EE relationships (Lobban, Barrowclough, & Jones, 2006).

High EE in caregivers is positively linked to negative caregiving appraisals, distress and less adaptive (avoidant) coping (Kuipers et al., 2006; Moller-Leimkuhler, 2005; Raune et al., 2004). The relationship between EE and negative appraisals of caregiving experience is already evident at the first episode of psychosis (Raune et al., 2004). Phillips, Pearson, Feifei, Minjie and Yang (2002) found that the effect of stigma on family members of people with schizophrenia was significantly greater if the family member had a high level of EE. Recently, EOI has also been associated with worse physical health among caregivers (Breitborde, Lopez, Chang, Kopelowicz, & Zarate, 2009). These findings suggest that high EE behaviour may be an understandable attempt to reduce the perceived stressfulness of the caring role (Raune et al., 2004).

1.5.2 Expressed emotion and posttraumatic stress symptoms

Within a framework that conceptualises high EE as a strategy to reduce perceived stress, it is possible that carers who have experienced traumatic life events related to their caring role and are experiencing posttraumatic stress symptoms as a result, will also exhibit high EE. Kavanagh (1992) proposes an interactive model of EE and psychiatric

relapse, in which high EE among carers could be both a cause of, and a response to, the psychiatric relapse among individuals with psychosis. High EE among caregivers may be a response to, and an indicator of stress that arises from coping with difficult, disturbed and uncontrollable behaviour often associated with psychiatric relapse (Chan, 2010; Hooley, Rosen, & Richters, 1995; Raune et al., 2004). Similarly, it has been suggested that EOI and criticism are adaptive responses to threatened loss (Patterson et al., 2005). If high EE is conceptualised as representing a carer's attempt to cope with an individual's illness, then it has been argued that high EOI carers might be appraising their situation differently and thus adopting different strategies from those of high critical carers (Barrowclough et al., 1994). Grice et al. (2009) found that low EE carers attributed more responsibility to the service user for positive events, than high EOI carers. The authors suggested that this may be a protective strategy used by low EE carers.

One study investigating posttraumatic stress symptoms in parents of children with acute burns demonstrated the importance of family conflict in the development of PTSD or possibly family cohesion in the prevention of PTSD (Hall et al., 2006). The results suggested that parental anxiety predicted increased parent-child conflict; and increased conflict with their children was directly related to the development of PTSD symptoms in parents. The authors suggested that anxious parents may develop active avoidant strategies that produce conflict with their children such as restricting their child's activities to reduce risk of further injury. Further, it was suggested that ongoing conflict may prevent the processing of trauma and may maintain PTSD symptoms. They also found that conflict with extended family before the trauma was predictive of acute dissociative responses in parents. It is possible that a similar process may occur with carers of people with psychosis. For instance, it could be that greater expressions of

criticism by carers (high EE) may be related to posttraumatic stress symptoms in carers especially if criticism is an indication of conflict between the carer and the service user. The links between EOI and controlling behaviours in carers of people with psychosis (Peterson & Doherty, 2004) also lend some support to the suggestion that overprotective behaviours in carers may generate interpersonal conflict which is then associated with higher posttraumatic stress symptoms in carers. Peterson and Doherty (2004) suggest that high EOI parents may be particularly likely to make attempts to control the patient because they experience more intense distress surrounding the patient's illness, which elicits a stronger desire to protect the patient from further problems. It could be hypothesised that the conflict that this stance creates and the avoidance associated with overprotection, may prevent the processing of trauma and maintain posttraumatic stress symptoms in high EOI carers.

Posttraumatic stress symptoms have been found to impact on other relationships. For instance, posttraumatic stress symptoms including anger and hostility have also been found to impact on veterans' relationships (Figley, 1986; Riggs, Byrne, Weathers, & Litz, 1998; Williams, 1980). Research has shown changes in marital relations among couples where one partner has PTSD, including an increase in conflict (Solomon et al., 1992).

Carer distress has already been linked to high EE therefore it is likely that carer posttraumatic stress symptoms will also be associated with high EE, particularly if posttraumatic stress symptoms relate to conflict, avoidance, stigma, feared loss, self-blame and overprotection in carers. As outlined above, both self-blame and avoidant coping have been associated with high EE in carers and according to the cognitive model of PTSD (Ehlers & Clark, 2000), cognitions of self-blame and avoidance

behaviour play an important role in the onset and maintenance of PTSD. Furthermore, the conceptualisation of EE as an adaptive coping strategy may suggest that carers who have experienced stressful or traumatic life events related to their caring role may exhibit EOI and/or criticism and that, amongst other variables, the type of high EE relationship may be dependent upon the nature of the stressor, coping strategies and/or caregiving appraisals.

Boye et al. (1998) explored the relationship between posttraumatic stress symptoms and EE status in carers of people with psychosis and hypothesised that high EE could be linked to a stress response syndrome. Boye and colleagues used questions from a more general distress measure (General Health Questionnaire-30; Goldberg, 1972) to make ad-hoc subscores of intrusion, avoidance and psychophysiological activation and then examined whether high EE status groups differed on these scores. In this study, relatives with consistently high EOI level were found to have higher subscores of intrusion and psychophysiological activation than relatives with consistently low EOI level. The authors argued that EOI characteristics such as exaggerated emotional responses, preoccupation and over-identification with the patient, could all be symptoms of intrusion because intrusion is characterised by: "unbidden ideas, preoccupation with themes related to the life event, and sudden rushes of feelings" (p. 497). They admitted symptoms of avoidance and psychophysiological activation were more difficult to elicit from the EOI definition but argued that intrusion is more directly related to the impact of trauma and is a better predictor of PTSD symptoms than avoidance. The authors concluded that while EOI could be linked to a stress response syndrome in some relatives, this did not seem to be the case for critical comments or the presence of hostility. The methodological limitations of this study, specifically the execution of several post-hoc analyses and the less than optimal use of the GHQ-30 to measure

posttraumatic stress symptoms, were acknowledged by the authors and a recommendation made to use assessments specifically designed to measure posttraumatic stress symptoms in future research.

1.6 Physical Health and Sleep

Caregiving burden has been associated with physical health problems (Gutierrez-Maldonado et al., 2005; Perlick et al., 2005) and sleep disruption (Phillips et al., 2009). Sleep disruption has been associated with depression and anxiety in various caregiver groups (Phillips et al., 2009; Brummett et al., 2006). Furthermore, Phillips et al. (2009) found that sleep quality mediated the relationships between caregiving burden and both depression and anxiety. It is possible that posttraumatic stress symptoms in carers may be contributing to these problems. Several studies have demonstrated that posttraumatic stress symptoms are associated with elevated health symptoms (Kimerling, Clum, & Wolf, 2000; Wolf, Schnurr, Brown, & Furey, 1994). Researchers have proposed multiple biological mechanisms to explain the impact of PTSD on health (Friedman & Schnurr, 1995) including chronic autonomic hyperarousal (McFarlane, Atchison, Rafalowicz, & Papay, 1994) and sleep disturbance (Friedman & Schnurr, 1995).

Sleep difficulties are common among individuals with PTSD (Ohayon & Shapiro, 2000), reflect a core symptom of increased arousal in PTSD (American Psychiatric Association, 2000), and may even be a predictor of the development of PTSD (Harvey & Bryant, 1998). In addition to more common sleep complaints, such as difficulty initiating and maintaining sleep, specific sleep disturbances have been reported in individuals with PTSD, including trauma-related nightmares, nocturnal intrusive memories, sleep terrors, nocturnal panic attacks and dream enactment behaviours (Germain, Hall, Krakow, Shear, & Buysee, 2005).

1.7 Intrusive Imagery

1.7.1 Intrusive imagery across disorders

Mental images have been defined as "perceptual information that arises from memory rather than from information being registered directly by the senses" (Hirsch & Holmes, 2007). Mental images were originally conceptualised as visual images in the mind's eye however it is now recognised that imagery can involve multiple sensory modalities, including sight, sound, smell and body sensations (Kosslyn, Ganis, & Thompson, 2001). Recent studies have explored the qualities (i.e., vividness, sense of nowness, and emotional re-experiencing) and impact of intrusions, and associated emotions (i.e., level of interference, uncontrollability, and distress) across a range of disorders (e.g., Patel et al., 2007; Gregory, Brewin, Mansell, & Donaldson, 2010).

Recurrent and intrusive images are included in the diagnostic criteria (American Psychiatric Association, 2000) for PTSD and obsessive-compulsive disorder; however they are a common feature in a range of other disorders and are now recognised as a transdiagnositic phenomenon (Brewin, Gregory, Lipton, & Burgess, 2010). Intrusive images have been found to occur in people suffering from specific phobias (Pratt, Cooper, & Hackmann, 2004), social phobia (Hackmann, Surawy, & Clark, 1998), bulimia nervosa (Somerville, Cooper, & Hackmann, 2007), health anxiety (Muse, McManus, Hackmann, Williams, & Williams, 2010; Wells & Hackmann, 1993), agoraphobia (Day, Holmes, & Hackmann, 2004), obsessive-compulsive disorder (Speckens, Hackmann, Ehlers, & Cuthbert, 2007), body dysmorphic disorder (Osman, Cooper, Hackmann, & Veale, 2004), complicated grief (Boelen & Huntjens, 2008), depression (Kuyken & Brewin, 1994; Patel et al., 2007), bipolar affective disorder (Gregory et al., 2010) and suicidality (Holmes, Crane, Fennell, & Williams, 2007). The

proportion of people who suffer from intrusive images varies from 44% to 100% of patients across these disorders (Schultze, 2009).

Despite being a feature across disorders, studies have found that the content and meaning associated with intrusive images vary according to individual concerns and frequently correspond with the concerns of the given diagnostic group (Holmes & Mathews, 2010). For example, people with bulimia experience intrusive imagery relating to their concerns about body image and weight (Somerville et al., 2007) whereas people with spider phobias experience images of spiders looking larger than life (Pratt et al., 2004).

1.7.2 Intrusive imagery in carers of people with psychosis

Relatively little is known about the experience of intrusive images in carers. Recent studies have begun to measure intrusions in carers of patients suffering from dementia (Ulstein et al., 2008) and in carers of people with psychosis (Barton & Jackson, 2008; Loughland et al., 2009; Boye & Matt, 2002). These studies have used self-report measures of posttraumatic stress which include several items relating to intrusions. To the author's knowledge, there have been no publications systematically assessing intrusive imagery in detail (e.g., qualities, impact and associated emotions) in carers of people with psychosis.

Intrusive images are an important clinical phenomenon because they appear to play a role in the maintenance of disorders (e.g., Brewin, Reynold, & Tata, 1999; Ehlers & Clark, 2000). Holmes and Mathews (2010) outline how imagery can influence and maintain a person's emotions, behaviours and beliefs about the self and world. Application of this theoretical framework to carers of people with psychosis suggests

how intrusive imagery may influence and maintain distress, including posttraumatic stress symptoms and depression. For example, in the case of carer who has an intrusive image of their loved one dead from suicide, the carer may be more likely to believe that there is a current threat of suicide. It could be argued that an increase in the conviction of this belief may impact on their behaviour and affect. For example, in this case it is possible that a carer may be unwilling to engage in social activities for fear of leaving their loved one at home alone and may also experience elevated levels of distress and anxiety. It could be hypothesised that this may then increase the likelihood of the carer withdrawing and becoming socially isolated. This theoretical framework has not, to date, been explored in research with carers of people with psychosis. However, it seems important to begin the process of understanding the content, qualities and impact of intrusive images on carers of people with psychosis as well as the meanings associated with these images.

1.8 Rationale and Aims

In summary, elevated levels of psychological distress have been documented in carers of people with psychosis (Kuipers & Bebbington, 2005; Roick et al., 2007), which have been related to negative appraisals of caregiving experiences (burden) (e.g., Onwumere et al., 2008; Szmukler et al., 1996), and high EE (Kuipers et al., 2006). In addition to chronic stressors, research suggests that carers experience events in which they perceive their life has been threatened (Loughland et al., 2009) and have described feelings of fear and helplessness in relation to their caring role (Wane et al., 2009). Evidence from a small number of studies suggests that a significant number of carers of people with psychosis experience posttraumatic stress symptoms including avoidance, intrusions, and arousal (Barton & Jackson, 2008; Loughland et al., 2009; Boye & Malt, 2002). It is unclear, however, how these symptoms relate to a broader range of carer characteristics.

The application of a stress and coping framework, including components from the cognitive model of PTSD (Ehlers & Clark, 2000), may help us to understand the relationship between posttraumatic stress symptoms and well-being in carers, and may also suggest areas in which to target interventions in this population. This study aims to explore posttraumatic stress symptoms in a sample of carers of people with psychosis, including intrusive imagery, and to examine the relationship between posttraumatic stress symptoms, well-being and caregiving experiences. In line with the theoretical models of stress and coping, the following hypotheses were made.

1.8.1 Primary hypotheses

In carers of people with psychosis:

1. Greater levels of posttraumatic stress symptoms will be associated with negative caregiving appraisals and negative appraisals of trauma
2. Greater levels of posttraumatic stress symptoms will be associated with greater levels of avoidant coping and poor social support
3. Greater levels of posttraumatic stress symptoms will be associated with distress

1.8.2 Secondary hypotheses

In carers of people with psychosis:

1. Greater levels of posttraumatic stress symptoms will be associated with greater levels of expressed emotion
2. Greater levels of posttraumatic stress symptoms will be associated with lower reported physical health including greater degree of sleep disturbance

2 Method

In this section, the methods and materials used for data collection are described in detail. The chapter begins with a review of the study design and recruitment pathways. A description of administered questionnaires and semi-structured interviews is then presented, followed by an outline of the study procedure. The chapter concludes with details of ethical approval, power analysis and planned data analyses.

2.1 Design

The design was cross-sectional. All participants completed a series of questionnaires and interview-based tasks over a 1-1.5 hour session with the researcher.

2.2 Recruitment

Participants were recruited from psychosis teams within the South London and Maudsley NHS Foundation Trust and Oxleas NHS Foundation Trust including: Support and Recovery and Early Intervention teams. Participants were also recruited from carer support groups in south London.

Following ethical approval to recruit from the NHS, the team leaders and consultant psychiatrists and/or clinical psychologists of each psychosis team were approached to gain permission to recruit from their caseload. A short presentation of the research was given at each team's clinical review meeting and questions from team members were answered. Professional Information Sheets were given to all staff (see Appendix 1).

Administrators and/or care coordinators within each psychosis team were asked to identify carers of people with psychosis from the administrative record databases, including the Trust's integrated electronic systems. Administrators and/or care

coordinators then provided eligible carers with brief details of the study and requested that carers contact the researcher if they were interested in participating in the study, or if they had any questions about the study. Interested carers were sent a cover letter, Participant Information Sheet and Consent Form (see Appendices 2 to 4), either in the post or via email. A follow up phone call was then made to these carers to answer any questions and to determine whether they would like to be involved in the study. If potential participants agreed to participate in the research, they were invited to meet the researcher at a location convenient for them, either at the service user's clinic team's base, at the Institute of Psychiatry, King's College London, or at their home.

Recruitment from carer support groups occurred in a similar manner with requests made to group organisers to present details of the research to carers at a group meeting. A short presentation was given to group members and interested carers were provided with information sheets. Follow up telephone calls were then made to these carers as above.

Recruitment was carried out over a five month period with the researcher meeting with participants between November 2011 and March 2012.

2.3 Inclusion and Exclusion Criteria

Participants were eligible for inclusion if they:

- Were aged 18 or over
- Fulfilled the following definition of being a carer. Carers were defined as the: parents, relatives, spouses or partners of an individual with psychosis, who identify themselves as a carer and have regular face-to-face weekly contacts with the individual with psychosis for at least ten hours including phone contact.

Similar definitions have been employed in previous research (e.g., Kuipers et al., 2006)

Potential participants were excluded, if they:

- Had insufficient English language skills to complete the written and verbal based assessments

2.4 Measures

2.4.1 Demographic Details Form (see Appendix 5)

Demographic data (e.g., age, gender, ethnicity, first language, relationship status, and employment status) were collected by interview at the start of the assessment. Basic information about the caregiving relationship was also collected (e.g., age of service user, relationship to service user, and whether or not the carer was living with the service user). See Appendix 5 for details.

2.4.2 Impact of Events Scale-Revised (IES-R; see Appendix 6)

The Impact of Events Scale-Revised (Weiss & Marmar, 1997) includes three subscales based on the *DSM-IV* cluster criteria for PTSD (intrusive thoughts, avoidance, and arousal). Participants were asked to rate 22 statements relating to their caring role, on a 5-point scale ranging from 0 (not at all) to 4 (extremely). This measure has been previously used with carers of people with psychosis in order to measure PTSD symptoms (Loughland et al., 2009; Barton & Jackson, 2008) and is a reliable measure of posttraumatic stress (Creamer, Bell, & Failla, 2003). The IES-R correlates highly with the PTSD checklist (PCL), suggesting that scores >1.5 provide optimum diagnostic accuracy against the PCL (Creamer et al., 2003). It has high test-retest reliability for use as a repeated measure (Sundin & Horowitz, 2002). Participants who identified a specific traumatic event related to the caring role during the administration of the adapted SCID

module were instructed to complete the IES-R in relation to this event. All other carers were asked to complete the questionnaire in relation to the caring role in general.

2.4.3 Adapted Structured Clinical Interview for DSM Disorders (SCID-I), PTSD Module (see Appendix 7)

The Structured Clinical Interview for DSM-IV-TR (First, Spitzer, Gibbon & Williams, 2002), PTSD module was administered to establish whether carers met diagnostic criteria for PTSD. The PTSD module of the SCID-I systematically assesses the history of exposure to a traumatic event or stressor (Criterion A) and symptoms from each of three symptom clusters: persistent re-experiencing (Criterion B), avoidance (Criterion C) and physiological arousal (Criterion D). In addition, the module assesses whether these symptoms cause clinical significant distress or impairment in social, occupational, or other functioning (Criterion F). A DSM-IV-TR diagnosis for current disorder is met if the patient meets criteria in each area, with symptoms lasting at least one month and being present in the past six months. Several modifications were made to the administration of the PTSD module to suit the current sample. First, the interview included an item designed to identify traumatic events specifically related to caring for a person with psychosis (see Appendix 7). In addition, the interview was only completed in relation to traumatic events associated with the caring role. The SCID-I PTSD module provides specific prompts and follow-up inquiries, intended to be read verbatim to respondents, to assess the presence or absence of each DSM-IV-TR PTSD symptom. Symptom presence is rated on a 3-point confidence scale (from *absent or false* to *threshold or true*) based on the interviewer's interpretation of the respondents' answers to the prompts. The interviewer was trained in the SCID-PTSD using the SCID manual and workshop videos.

2.4.4 Experience of Caregiving Inventory (ECI; see Appendix 8)

The Experience of Caregiving Inventory (Szmukler et al., 1996) is a 66-item self-report questionnaire developed to assess caregiver's negative and positive appraisals of their experience of caring for someone with mental health problems. Respondents rate how often they have thought about a particular issue in the last month prior to completing the questionnaire on a 5-point scale ranging from 0 (*never*) to 4 (*nearly always*). There are 10 subscales, 8 relate to negative aspects of care-giving (e.g., stigma, loss) and 2 relate to the positive aspects (i.e., positive personal experiences and good aspects of the relationship). These subscales are summed to create two summary subscale scores: negative caregiving appraisals and positive caregiving appraisals. The current study used both subscale and summary subscale scores. Higher scores indicate more negative or positive appraisals. The scale has good reliability and validity (Szmukler et al., 1996) and has been used extensively with carers of people with psychosis (e.g., Onwumere et al., 2008; Tennakoon et al., 2000; Addington et al., 2003).

2.4.5 Posttraumatic Cognitions Inventory (PTCI; see Appendix 9)

The Posttraumatic Cognitions Inventory (PTCI; Foa et al., 1999) is a 33-item inventory measuring negative cognitive appraisals of trauma and its sequelae: negative cognitions about self (21 items); negative cognitions about the world (7 items); and self-blame for the trauma (5 items). Each statement is rated according to the extent of agreement ranging from 1 (*totally disagree*) to 7 (*totally agree*). Items are scored on 7-point response scales and averaged to produce three scale scores. Subscale totals are summed to get an overall total score. The three factors have been found to: discriminate well between individuals with and without PTSD; correlate moderately to strongly with measures of PTSD, depression and general anxiety; and have excellent internal consistency and good test-retest reliability (Foa et al., 1999). Participants who identified

a specific traumatic event related to the caring role during the administration of the adapted SCID module were instructed to complete the PCTI in relation to this event. All other carers were asked to complete the questionnaire in relation to the caring role in general.

2.4.6 Abbreviated Coping Orientations to Problems Experienced (COPE) Inventory (see Appendix 10)

The COPE Inventory (Carver, Scheier, & Weintraub, 1989; Carver & Scheier, 1994) assesses an extensive range of functional and dysfunctional coping styles on a 4-point Likert scale of frequency of use. It comprises 15 distinct scales. The abbreviated COPE includes all scales but has 2 questions per scale instead of the usual 4. The COPE has demonstrated reliability and validity (Carver et al., 1989; Carver, Kus, & Scheier, 1994). As in previous studies with carers of people with psychosis (Raune et al., 2004; Kuipers et al., 2006; Onwumere et al., 2010), the current study will use the avoidant coping scale comprising the summed scores of behavioural disengagement, mental disengagement, alcohol/drug use and denial subscales.

2.4.7 Confidante Question (see Appendix 11)

The confidante question was used to provide an indication of social support and network by having carers answer “yes” or “no” to the question: “Do you have someone in whom you can confide”? This question has been used in previous research with carers of people with psychosis (e.g., Onwumere et al., 2009) and in physical health studies (Dickens et al., 2004).

2.4.8 The General Health Questionnaire-28 (GHQ-28; see Appendix 12)

The General Health Questionnaire-28 (Goldberg & Hillier, 1979) is a distress and well-being scale. For each item, respondents are required to rate the occurrence of a particular symptoms on a 4-point scale that ranges from a *better/healthier than normal* option, through a *worse/more than usual* to a *much worse/more than usual option*. The exact wording depends upon the item. There are four subscales: somatic symptoms; anxiety and insomnia; social dysfunction; and depression. There are four possible methods for scoring the questionnaire including: GHQ scoring method (0-0-1-1); Likert scoring method (0-1-2-3); Modified Likert scoring (0-0-1-2); and C-GHQ scoring (0-0-1-1 for items where agreement indicates health and 0-1-1-1 for items where agreement indicates illness). The current study used the Likert scoring method (0-1-2-3). Using this method, the maximum score possible is 84 and a score of >24 suggests "psychiatric caseness" (Goldberg et al., 1997). The GHQ is a widely used and well validated measure in research with carers of people with psychosis (e.g., Barton & Jackson, 2008; Onwumere et al., 2009).

2.4.9 Hospital Anxiety and Depression Scale (HADS; see Appendix 13)

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) contains 14 items rated on a 4-point scale indicating the strength of agreement with each item. Seven items are related to anxiety and seven to depression. This measure has been widely used with carers of people with psychosis (e.g., Boye & Malt, 2002; Fortune et al., 2005). A score of greater than or equal to 11 on either subscale suggests probable clinical disorder.

2.4.10 The Five Minute Speech Sample (FMSS; see Appendix 14)

The Five Minute Speech Sample (Magana et al., 1986) is a short, direct measure of expressed emotion (EE). It instructs carers to speak for five minutes about the person they care for and their relationship (see Appendix 14 for instructions). The interview is audio recorded and transcribed verbatim, and subsequently rated on four dimensions: quality of initial statement, quality of relationship, criticism and emotional over-involvement. Recordings can be classified as being either high or low EE. Classifications of high EE are given to those high on the emotionally over-involved (EOI) and/or criticism dimensions. A carer would be classified as high EE (criticism) if they make one or more critical comments, or if the quality of the initial statement is negative. A classification of high EE on the EOI dimension is given for one or more of the following characteristics: five or more positive remarks, excessive details from the past, and one or more statements of attitude (Magana et al., 1986).

The Camberwell Family Interview (CFI; Brown & Rutter, 1966; Rutter & Brown, 1966; Vaughn & Leff, 1976) is considered the "gold standard measure" for EE (Hooley & Parker, 2006; Van Humbeek, Van Audenhove, De Hert, Pieters, & Stroms, 2002). It involves a direct interview with the key relatives of the individual with psychosis. The CFI continues to be utilized as a measure of EE due its prospective predictive power and robust reliability. However it is not considered the most economical instrument due to the length of training required and time involved in administration and rating (four to five hours per person; Van Humbeeck et al., 2002). As a result, other interview-based instruments have been developed, including the FMSS, with the intention of providing a reliable but timely alternative to the CFI. In a review of measures of EE, Van Humbeeck et al. (2002) recommends the FMSS as the best alternative to the CFI despite its underestimation of high EE. The FMSS has been widely used in research with carers

of people with psychosis (e.g., Bachmann et al., 2002; Barrowclough, Lobban, Hatton, & Quinn, 2001; Heikkila et al., 2002; Lobban et al., 2006).

2.4.11 RAND 36-item Health Survey Questionnaire (RAND-36; see Appendix 15)

The RAND 36-item Health Survey (Hays, Sherbourne, & Mazel, 1993) comprises 36 items that assess eight health concepts: physical functioning (10 items), social functioning (two items), role limitations due to physical problems (four items), role limitations due to emotional problems (three items), mental health (five items), energy and vitality (four items), pain (two items), and general perception of health (five items). In terms of scoring, every item is transformed linearly to a 0-100 possible range (percentage of total score) and then all items within the same scale are averaged together (Hays & Morales, 2001). The SF-36 Health Survey (Ware & Sherbourne, 1992) has been used in research with carers of people with psychosis (e.g., Gutierrez-Maldonado et al., 2005). The RAND-36 has the same questions as the SF-36 (Ware & Sherbourne, 1992), but is scored slightly differently.

2.4.12 Pittsburgh Sleep Quality Index (PSQI; see Appendix 16)

The Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) is a 19 item self-rated questionnaire which assesses sleep quality and disturbances over a one-month time interval. There are seven "component" scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The sum of scores for these seven components yields one global score (range 0-21). The current study used the PSQI global score, with "0" indicating no difficulty and "21" indicating severe difficulties in all areas. The PSQI has been used in research to assess sleep quality in carers (e.g., Carter, 2003; Pal et al., 2004).

2.4.13 Intrusion Interview (see Appendix 17)

A semi-structured interview, based upon previous interviews (Hackman, Clark, & McManus, 2000; Hackman, Ehlers, Speckens, & Clark, 2004; Patel et al., 2007) was used to investigate the presence and characteristics of intrusive and recurrent images and associated memories (see Appendix 17). The interview began by introducing and normalising the experience of intrusive images and exploring a positive image with the participant as an illustration. Following this, the researcher asked if the participant had ever experienced any recurrent negative intrusive images either: when they are stressed, anxious or depressed; associated with a past traumatic event; associated with the caring role; or associated with feared outcomes related to the caring role. If the participant reported recurrent negative intrusive images in the previous one month they were asked to focus on the image that was most distressing, with their eyes closed, and rate the image on content, vividness, frequency, distress, threat, controllability, and the degree of interference with daily life. Participants were also asked to rate the extent to which emotions and physical sensations accompanied the image, the degree to which the image felt real ("realness"), and the meaning associated with the image. If the participant had a memory associated with the negative intrusive image then the memory was then explored using the same questions that were asked in relation to the image. To reflect the difference between images and memories, the realness rating was replaced by asking the participant about the degree to which the event was experienced to be happening now ("nowness"; Holmes et al., 2007), and re-experiencing scales were included.

2.5 Procedure

At the beginning of each assessment an explanation about what the study involved was provided. Participants were provided with an opportunity to read through the Participant Information Sheet again (see Appendix 3) and have any questions answered. Participants then completed a consent form with the researcher (see Appendix 4).

Following the participants' consent to take part in the study, the researcher completed the demographic form. Participants were then asked to complete the FMSS. The order of administering the FMSS was designed to avoid a participant's beliefs about the service user being unduly influenced by their questionnaire responses. Following the FMSS interview, participants were administered the diagnostic interview, intrusion interview and the self-report questionnaires. Participants were given breaks whenever needed. All measures were usually completed during a single individual meeting with the carer, although for two carers the measures were completed across two sessions upon their request.

Once all measures had been administered participants were debriefed and given £15 reimbursement.

2.6 Power Calculations

A similar study explored the association between posttraumatic stress (as measured by IES-R; Weiss & Marmar, 1997) and negative caregiving appraisals (as measured by the ECI; Szmukler et al., 1996) in carers of people with psychosis and found a correlation of 0.49 (Barton & Jackson, 2008; Karen Barton, personal communication, February 10, 2011). Therefore the current study was powered for a correlation coefficient of 0.49, and used an alpha level of 0.05 for three main hypotheses where similar correlations

were expected. A 0.05 two-sided Fisher's z test of the null hypothesis that the Pearson correlation coefficient r = 0.00, will have 80% power to detect a r of 0.49 when the sample size is 31.

2.7 Ethical Approval

Ethical approval for the study was sought and granted by the National Research Ethics Service Committee London – Stanmore (REC reference: 11/LO/0498). The research received approval from research and development offices at South London and Maudsley NHS Foundation Trust (Reference: R&D2011/056) and Oxleas NHS Foundation Trust. Written permission to recruit participants from within the South London and Maudsley NHS Foundation Trust was also obtained from the Psychosis Clinical Academic Group (CAG) Research Sub-Committee.

2.8 Analysis

Spearman's Rank Order Correlation's (rho) were used to assess the relationship between posttraumatic stress symptoms and negative caregiving appraisals, trauma appraisals, avoidant coping, social support, distress, EE, sleep quality and physical health.

The percentage of participants in the total sample reporting recurrent intrusive images and associated memories was calculated. The percentage of people whose intrusive images and associated memories related to their caring role was also calculated. Descriptive statistics were reported for the characteristics associated with the intrusive imagery (e.g., distress, interference, and meaning).

An exploratory analysis was used to assess the difference between participants who completed the IES-R in relation to the caring role in general with those who completed

the IES-R in relation to a specific traumatic event associated with the caring role. Mann-Whitney U Tests were used to determine if there were differences in posttraumatic stress symptoms, negative caregiving appraisals, trauma appraisals, avoidant coping, social support, distress, EE, sleep quality and physical health. T-tests were also used to compare results in this study with results of other studies.

Analyses were carried out using SPSS for Windows (PASW Statistic 18 Release 18.0.0, Jul 30, 2009). Power calculations for correlations were obtained using NQuery Advisor 4.0 (Elashoff, 2000). In order to compare results in this study with results in other studies, t-tests were calculated using the GraphPad QuickCals Web site: http://graphpad.com/quickcalcs/ ttest1.cfm?Format=SD (accessed May 2012), because the sample sizes, means and standard deviations were known for each study and therefore could be compared parametrically making Welch's adjustments for unequal variance.

3 Results

This section presents the results of the study. The demographic variables of the sample are described followed by a summary of the phenomenological data drawn from the intrusive imagery semi-structured interview. Statistical analyses comparing posttraumatic stress symptoms and other key variables are then presented.

3.1 Recruitment

In total, 32 carers participated in the study. Table 1 indicates the different recruitment sources. The recruitment process was a challenging and lengthy process, which comprised travelling to clinical team bases, carer support groups and participant homes. One participant was unable to complete the interviews due to no private space at their home and being unable to travel to the Institute of Psychiatry or meet with the researcher at the team base during office hours. Approximately 181 carers were approached to participate in the study (i.e., given brief details about the study and asked to contact the researcher if interested). Forty carers (22%) expressed an interest in the study and eight of these carers (20%) declined to participate after receiving further information about the study from the researcher. The final recruitment figure was 32 (80% of those who agreed to be contacted).

Table 1

Recruitment Sources

Recruitment source	***n* (%)**
South London Support and Recovery Teams	15(47%)
South London Support and Recovery Team - Support groups	7 (22%)
South London Carers Event	1(3%)
Psychological Interventions Clinic for outpatients with Psychosis	2(6%)
Greenwich Early Intervention Service	4(13%)
Consented to be contacted via other research at Institute of Psychiatry	3(9%)

The majority of participants preferred to be seen in their home, team base or other community building (*n* = 24, 75%) with the remaining quarter opting to complete the assessments at the Institute of Psychiatry (*n* = 8, 25%). There were two carers who did not complete the measures at the visit and requested to send them back later using a prepaid postage envelope. Two carers completed the research across two sessions. Despite the original estimates, the average assessment session lasted 2-2.5 hours, excluding travel time. Although the assessment protocol was adhered to by the researcher, most carers wanted to use some of the time to talk about their overall experiences not just to answer the research questions. The PTSD module of the SCID and Intrusion Interview in particular had potential to be distressing for carers, and thus adequate time was also needed at the end of sessions to debrief, as detailed in the ethical approval process.

3.2 Data Screening and Statistical Analyses

The data were analysed using the Statistical Package for the Social Sciences (SPSS) Version PASW Statistics 18.

3.2.1 Missing data

There was very little missing data across all self-report questionnaire measures (less than 1%). Case mean substitution technique was used when data were missing on less than 30% of items (Fox-Wasylyshyn & El-Masri, 2005). This method ascribes the participant's mean score based upon items that are present for that participant (Raymond, 1986). When missing data for a subscale of a measure was less than 30% for a particular participant on a specific subscale, it was replaced with the mean for that particular participants subscale. For Posttraumatic Cognitions Inventory (PTCI) and RAND 36-item Health Survey Questionnaire (RAND-36) subscale scores, the mean of

all available items was taken even when missing items exceeded 30%, as per scoring instructions. This occurred only in three instances: for one participant within the social functioning (one out of two items missing) and the general health (four out of five items missing) subscales of the RAND 36; and for another participant on the Self-Blame subscale on the PCTI (one out of two items missing). If missing data exceeded 30% within a subscale where items were summed to obtain subscale scores, then the particular case was excluded for analyses for which the missing data was required. One carer did not complete any items on the Hospital Anxiety and Depression Scale (HADS) or on three of the RAND-36 subscales (energy and fatigue, emotional well-being, and pain); therefore this participant was excluded from specific analyses where these data were required. The participant who did not complete any of the interviews was excluded from specific analyses where interview data was required.

3.2.2 Outliers and normality

In order to detect potential outliers, standardized scores (z-scores) were examined to identify those in excess of 3.29 (Tabachnick & Fidell, 1996). No outliers were identified. Data were examined to establish whether they met the assumptions of normal distribution using Kolmogorov-Smirnov test of normality in conjunction with visual inspection of quantile-quantile (Q-Q) plots and the values of skew and kurtosis. A significant Kolmogorov-Smirnov test indicates a deviation from the normal distribution. This test can be limited in large samples because small deviations from the normal distribution are easily identified as significant, but do not indicate whether these deviations are significant enough to bias the statistical procedure. For this sample, it seemed unlikely this limitation would apply and it was therefore considered to be a reliable measure. Several variables were not normally distributed. For this reason the non-parametric statistic, Spearman Rank Order Correlation (rho), was used for all

correlational analyses. Spearman Rank Order Correlation (rho) was used even when variables were normally distributed in order to be consistent and allow comparison of results across analyses. Spearman correlation coefficient is about 95% as efficient as Pearson's correlation coefficient if both variables are normally distributed and more appropriate than Pearson's correlation if the assumptions of normality are violated (Field, 2009).

3.2.3 Level of significance and multiple testing

Due to the exploratory nature of the study all findings are reported as two-tailed significance. The power analysis calculated that 31 participants were needed for main hypotheses (using a p-value of 0.05): comparisons between posttraumatic stress symptoms and appraisals of caregiving experiences, negative appraisals of trauma, avoidant coping, social support and distress. Additional comparisons were made between posttraumatic stress and other key variables also using a p-value of .05. Although a p-value of 0.01 would have been more stringent for explorative research making multiple comparisons, this would have required a sample size of 44 to give 80% power to detect an effect size of r = 0.49. As it was not feasible to recruit such a large number of participants in the time available for the study these additional analyses were underpowered to correct for multiple testing and are therefore exploratory. The implications of the sample size, analyses strategy and reported results will be reviewed in the discussion section.

3.3 Demographic Data of the Sample

Most participants were female (84%, *n* = 27) and were aged between 19 and 83 years old (mean age = 49). The majority of participants were either unemployed (41%, *n* = 13) or retired (22%, *n* = 7). See Table 2 for details of demographic variables assessed.

The majority of participants identified themselves at White or Black/Black British. This largely reflects the demographic of the inner London urban areas where they were recruited.

Table 2

Socio-demographic characteristics for carers (N = 32)

Demographic categories	
Female Gender	27 (84%)
Age *M* (*SD*)	49 (14.92)
Occupation *n* (%)	
Employed full-time	5 (16%)
Employed part-time	3 (9%)
Self-employed	2 (6%)
Student	2 (6%)
Unemployed	13 (41%)
Retired	7 (22%)
Relationship status *n* (%)	
Single	7 (22%)
Divorced	7 (22%)
Widowed	3 (9%)
Married	13 (41%)
Cohabitating	2 (6%)
Ethnic Group *n* (%)	
White	18 (56%)
Mixed	2 (6%)
Asian or Asian British	1 (3%)
Black or Black British	9 (28%)
Other ethnic group	2 (6%)
First Language English *n* (%)	20 (63%)

3.4 Relationship between Carer and Service User

Service users were aged between 18 and 65 years old (mean age = 38). Duration of the caring role ranged from 2 months to 30 years (mean duration in months = 100; equivalent to 8 years 4 months). Most participants lived with the cared for person (*n* =

25, 78%) and for half of the participants, the service user was their son (*n* = 16, 50%). See Table 3 for details about the relationship between participant and service user.

Table 3

Relationship between carer and service user (N = 32)

Relationship characteristics	
Service user age *M* (*SD*)	38 (13.5)
Duration of caring in months *M* (*SD*)	100 (94)
Relationship of service user to carer *n* (%)	
Daughter	3 (9%)
Son	16 (50%)
Brother	1 (3%)
Partner	7 (22%)
Mother	4 (13%)
Friend	1 (3%)

3.5 Descriptive Data

3.5.1 Posttraumatic stress symptoms

Posttraumatic stress total scores for the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997) ranged within the sample from 0 to 3.05 (*M* = 1.32, *SD* = .87). Almost half (*n* = 14, 44%) had a total score greater than 1.5 on the IES-R. The IES-R correlates highly with the PTSD checklist (PCL), suggesting that scores >1.5 provide optimum diagnostic accuracy against the PCL (Creamer et al., 2003). Table 4 presents mean scores for IES-R total and subscale scores.

According to the SCID interview, one participant (3%) met full diagnostic criteria for PTSD in response to an event related to their caring role.

Table 4

Mean Impact of Event Scale-Revised (IES-R) total and subscale scores for carers (N=32)

IES-R Subscale Scores	***M***	***SD***
Avoidance	1.48	.96
Hyperarousal	1.26	1.00
Intrusion	1.23	.84
IES-R Total	1.33	0.88

Approximately half of the carers completed the IES-R in relation to a specific traumatic event related to the caring role (n = 15, 47%). Despite experiencing stressful life events related to the caring role, the remainder of carers (n = 17, 53%) completed the IES-R in relation to the caring role in general because one specific event could not be identified as the most upsetting or traumatic. A Mann-Whitney U test was conducted to compare posttraumatic stress symptom scores (as measured by the IES-R) for these two groups (i.e., those who rated the IES-R in relation to the caring role in general and those that rated it in relation to a specific event associate with their caring role). No significant difference was found in posttraumatic stress symptoms (IES-R total score) of those participants who rated the IES-R in relation to the caring role in general (Md = 1.14; n = 17) and those who rated the IES-R in relation to a specific event associated with the caring role (Md = 1.36; n = 15, U = 103, z = -.93, p = .36, r = 0.17. Mann-Whitney U tests were also used to compare the two groups of carers on all other measures. The only significant difference between the two groups was on a measure of anxiety (HADS). A Mann-Whitney U Test revealed a significant difference in anxiety level (as rated by the HADS) of carers who completed the IES-R in relation to the caring role in general (Md = 7, n = 16) and those who rated the IES-R in relation to a specific event (Md = 10, n = 15), U = 64.5, z = -2.20, p = .03, r = 0.39.

Carers indicated that they had experienced or witnessed a range of stressful life events related to their caring role (see Table 5). 77% of the sample (*n* = 24) reported that they had also experienced or witnessed a traumatic event in their life unrelated to their caring role, as measured by an open-ended question on the Adapted Structured Clinical Interview for DSM Disorders (SCID) PTSD module (First et al., 2002).

Table 5

Stressful life events related to caring role excluding data for one missing case (n = 31)

Stressful life event	***n* (%)**
Physical violence by service user	7 (23%)
Verbal abuse and/or threats by service user	20 (65%)
Involuntary hospital admission of service user	22 (71%)
Suicide attempt or self-harm by service user	19 (61%)
Informed of mental health diagnosis of service user[a]	17 (53%)
Psychiatric hospital environment due to admission of service user[a]	24 (75%)
Discrimination and/or stigma due to caring role	9 (29%)
Severe financial burden or bankruptcy due to caring role	17 (55%)
Other risky/unpredictable behaviour by service user	21 (68%)
Other traumatic or stressful event related to caring role	25 (81%)

[a] participants who experienced these events but stated they did not find them stressful or traumatic are excluded

3.5.2 Experience of caregiving, trauma appraisals, distress, anxiety, depression, avoidant coping, social support, sleep quality and physical health

Average scores for the negative caregiving appraisal summary scale and the positive caregiving appraisal summary scale of the Experiences of Caregiving Inventory (ECI; Szmukler et al., 1996) were 94.82 (*SD* = 42.8) and 37.9 (*SD* = 8.63) respectively. Mean and standard deviations for each subscale on the ECI are presented in Table 6.

Table 6

Experiences of Caregiving Inventory (ECI) scores for the whole sample (N = 32)

ECI subscale	***M***	***SD***
Negative caregiving subscales		
Difficult behaviours	13.19	8.59
Negative symptoms	11.97	7.64
Stigma	6.34	4.26
Problems with services	14.75	7.09
Effects on family	11.29	6.89
Need for backup	12.16	6.18
Dependency	12.75	4.81
Loss	12.37	6.34
Positive caregiving subscales		
Positive personal experiences	21.72	6.17
Good aspects of the relationship	16.18	3.89

Table 7 presents the mean scores and standard deviations for measures assessing trauma appraisals, anxiety, depression, distress, avoidant coping style, sleep quality and health. In response to the Confidante Question, all participants (N = 32, 100%) reported that they had someone in whom they could confide.

A score of greater than or equal to 11 on either subscale of the Hospital Anxiety and Depressions Scale (HADS; Zigmond & Snaith, 1983) suggests probable clinical disorder. The average score for the current sample was significantly below previous research looking at the levels of anxiety (M = 11.24, SD = 4.80; $t(64) = 2.20$, $p = 0.03$) and depression (M = 8.5, SD = 4.11; $t(62) = 3.26$, $p = 0.00$) in carers of people with psychosis using the HADS (Fortune et al. 2005). A score of greater than 24 on the General Health Questionnaire-28 (GHQ-28; Goldberg et al., 1997) suggests "psychiatric caseness". The average score for this sample fell slightly below this cut off (M = 23.35, SD = 14.25) with 14 (44%) participants scoring above the cut off for psychiatric caseness. The average score for the current sample was not significantly different from

previous research looking at distress in carers of people with psychosis (Onwumere et al., 2009; $M = 27$, $SD = 14.8$; $t(60) = 1.16$, $p = 0.25$).

Table 7

Scores on other key measures (N = 32 except where specified)

Measures	*M*	*SD*
Posttraumatic Cognitions Inventory (PCTI) subscales		
Self-blame for the trauma	1.88	1.20
Negative cognitions about the self	2.07	1.12
Negative cognitions about the world	3.35	1.61
Hospital Anxiety and Depression Scale (HADS)		
Anxiety[a]	8.71	4.88
Depression [a]	5.62	4.24
General Health Questionnaire-28 (GHQ-28) total score	23.35	14.25
GHQ-28 subscale scores		
Somatic symptoms	6.56	4.46
Anxiety and insomnia	6.56	4.84
Social dysfunction	7.56	3.16
Depression	2.69	3.68
Abbreviated COPE Avoidance Coping Scale	15.19	4.40
Global Pittsburgh Sleep Index (PSQI) Score	8.15	3.97
RAND-36 item Health Survey Questionnaire health concepts		
Physical Functioning	77.76	29.15
Social Functioning	67.58	30.10
Role limitations due to physical problems	62.50	41.64
Role limitations due to emotional problems	61.46	41.57
Emotional well-being[a]	64.52	22.69
Energy and vitality[a]	54.19	24.74
Pain[a]	70.89	27.77
General health	60.47	28.49

[a] $n = 31$

3.5.3 Expressed emotion

Five Minute Speech Samples (FMSS; Magana et al., 1986) were transcribed and then rated by the author. Seventeen speech samples (55%) were then rated by the author, an independent research assistant and primary supervisor (Juliana Onwumere, JO), an

experienced rater of EE and FMSS. Discussions were held between the three raters, initial disagreements discussed and a final decision reached regarding the ratings. A comparison in ratings between JO and the author for the double rated speech samples (*n* = 17) was made prior to discussions to agree on ratings. These double rated speech samples had 76% agreement of the EE classification; hence there was deemed to be good inter-rater reliability.

42% of participants (*n* = 13) were rated as being high EE on the FMSS. A detailed breakdown of categories and dimensions is presented in Tables 8 and 9.

Table 8

Expressed emotion categories for participants excluding missing data for one case (n = 31)

EE Category	***n* (%)**
Low EE ratings	
Low	6 (19%)
Borderline EOI	4 (13%)
Borderline critical	7 (23%)
Borderline EOI and borderline critical	1 (3%)
High EE ratings	
Critical	7 (23%)
Critical and borderline EOI	1 (3%)
EOI	1 (3%)
EOI and borderline critical	2 (6.5%)
EOI and critical	2 (6.5%)

Table 9

Expressed emotion dimensions as rated using the Five Minute Speech Sample excluding missing data for one case (n = 31)

EE Dimension	High EE *n* = 13	Low EE *n* = 18
Initial statement		
Positive	1 (8%)	3 (17%)
Neutral	11 (85%)	15 (83%)
Negative	1 (8%)	0 (0%)
Relationship		
Positive	0 (0%)	5 (28%)
Neutral	11 (85%)	13 (72%)
Negative	2 (15%)	0 (0%)
Critical comments		
0	4 (31%)	17 (100%)
≥ 1	9 (69%)	0 (0%)
Dissatisfaction		
Present	9 (69%)	8 (44%)
Absent	4 (31%)	10 (56%)
Emotional Overinvolvement		
Absent	8 (62%)	17 (100%)
Present	5 (38%)	0 (0%)
Positive comments		
0 - 4	12 (92%)	14 (78%)
≥5	1 (8%)	4 (22%)

3.6 Primary Hypothesis 1: Greater levels of posttraumatic stress symptoms will be associated with caregiving appraisals and negative appraisals of trauma

The relationship between experiences of caregiving (as measured by the ECI) and posttraumatic stress symptoms (as measured by the IES-R) was investigated using Spearman Rank Order Correlation (see Table 10 for results). As predicted there was a moderate positive correlation between negative caregiving appraisals and posttraumatic stress symptoms as measured by IES-R Total score (Spearman's rho = .49, $p < 0.005$). There were large positive correlations between posttraumatic stress symptoms and

appraisals of stigma (Spearman's rho = .63, $p < .005$) and appraisals of the effects on family (Spearman's rho = .52, $p < .005$), and a moderate positive correlation between posttraumatic stress symptoms and appraisals of problems with services (Spearman's rho = .47, $p < .005$). Please see Appendix 18 for scatterplots of correlations between posttraumatic stress symptoms and key variables for all hypotheses.

Table 10

Correlations between posttraumatic stress symptoms in carers and experiences of caregiving (N = 32)

	Intrusion	**Avoidance**	**Hyperarousal**	**IES-R Total**
ECI Total Negative subscale	.42*	.42*	.53**	.49**
ECI Total Positive subscale	-.24	-.24	-.41*	-.31
ECI negative subscales				
Difficult behaviours	.25	.27	.38*	.32
Negative symptoms	.21	.22	.38*	.30
Stigma	.58**	.55**	.65**	.63**
Problems with services	.41*	.44*	.46**	.47**
Effects on family	.43*	.50**	.58**	.52**
Need for backup	.28	.32	.41*	.35*
Dependency	.38*	.28	.43*	.38*
Loss	.39*	.34	.40*	.40*
ECI positive subscales				
Positive personal experiences	-.13	-.13	-.28	-.19
Good aspects of relationship	-.29	-.32	-.41*	-.36

*$p < .05$, two-tailed. ** $p < .005$, two-tailed.

The relationship between negative appraisals of trauma (as measured by the PTCI) and posttraumatic stress symptoms (as measured by the IES-R) was investigated using Spearman Rank Order Correlation (see Table 11 for results). There were strong positive correlations between both carer negative cognitions about the self and self-blame for the

trauma, and IES-R total and subscale scores. There was a moderate relationship between negative cognitions about the world and hyperarousal.

Table 11

Correlations between measures of trauma appraisals and posttraumatic stress symptoms in carers (N = 32)

	Intrusion	**Avoidance**	**Hyperarousal**	**IES-R Total**
Negative cognitions about the self	.54**	.66**	.63**	.64**
Negative cognitions about the world	.19	.29	.41*	.31
Self-blame for the trauma	.64**	.62**	.51**	.64**

*$p < .05$, two-tailed. ** $p < .005$, two-tailed.

3.7 Primary Hypothesis 2: Greater levels of posttraumatic stress symptoms will be associated with greater levels of avoidant coping and poor social support

All participants ($N = 32$; 100%) reported that they had someone in whom they could confide. The relationship between posttraumatic stress symptoms (as measured by the IES-R) and avoidant coping style (as measured by abbreviated COPE) was investigated using Spearman Rank Order Correlation. There were strong positive relationships between the avoidant coping scale and IES-R total (rho = .65, $n = 32$, $p < .005$); Intrusion (rho = .55, $n = 32$, $p < .005$); Avoidance (rho = .63, $n = 32$, $p < .005$); and Hyperarousal (rho = .67, $n = 32$, $p < .005$) scores. Higher levels of posttraumatic stress symptoms were associated with greater use of avoidant coping strategies.

3.8 Primary Hypothesis 3: Greater levels of posttraumatic stress symptoms will be associated with distress

The relationship between distress, depression and anxiety (as measured by the GHQ-28 and HADS) and posttraumatic stress symptoms (as measured by IES-R) was investigated using Spearman Rank Order Correlation (see Table 12). There were strong positive correlations between posttraumatic stress symptoms and levels of distress, depression and anxiety in carers.

Table 12

Correlations between distress, anxiety and depression and posttraumatic stress symptoms in carers (N = 32)

	Intrusion	**Avoidance**	**Hyperarousal**	**IES-R Total**
HADS				
Anxiety[a]	.55**	.60**	.77**	.66**
Depression[a]	.45*	.53**	.62**	.55**
GHQ-28				
Somatic Symptoms	.40*	.34	.53**	.44*
Anxiety and insomnia	.47**	.45*	.63**	.54**
Social dysfunction	.30	.35	.43*	.38*
Depression	.48**	.61**	.59**	.59**
GHQ-28 Total	.48**	.47**	.62**	.55**

[a] $n = 31$

*$p < .05$, two-tailed. ** $p < .005$, two-tailed.

3.9 Secondary Hypothesis 1: Greater levels of posttraumatic stress symptoms will be associated with greater levels of expressed emotion

The relationship between EE (as measured by the FMSS) and posttraumatic stress symptoms (as measured by IES-R) was investigated using point-biserial correlation (r_{pb}), except for associations with number of criticism and positive remarks, for which Spearman Rank Order Correlations were used (see Table 13). There were no significant

correlations found between expressed emotion (categorised as high and low) and overall posttraumatic stress symptoms (IES-R Total; $r = 0.1$, $n = 31$, $p = .97$).

Table 13

Correlations between expressed emotion and posttraumatic stress symptoms in carers excluding missing data for one case (n = 31)

	Intrusion	**Avoidance**	**Hyperarousal**	**IES-R Total**
High/low EE status	.01	-.05	.03	.01
Emotional Overinvolvement	-.07	.08	.12	.03
Critical	-.03	-.08	-.09	-.07
EE dimensions				
Number of criticism[a]	.03	-.07	.01	-.01
Dissatisfaction	-.03	.15	.21	.12
Emotional display	.22	.08	.18	.14
Statement of attitude	-.20	-.07	-.11	-.12
Self-Sacrifice/overprotective/ Lack of objectivity	-.01	-.04	.09	-.01
Positive remarks[a]	.08	.08	.08	.08

[a] Spearman correlation coefficient rather than point biserial correlation
*$p < .05$, two-tailed. ** $p < .005$, two-tailed.

3.10 Secondary Hypothesis 2: Greater levels of posttraumatic stress symptoms will be associated with lower reported physical health including greater degree of sleep disturbance

The relationship between posttraumatic stress symptoms (as measured by the IES-R) and physical health (as measured by RAND-36) was investigated using Spearman Rank Order Correlation. Strong negative correlations were found between general health subscale and IES-R total and subscale scores. Other strong and moderate relationships were found between the RAND-36 subscales and IES-R total and subscale scores (see Table 14).

The relationship between posttraumatic stress symptoms (as measured by the IES-R) and sleep quality (as measured by abbreviated PSQI) was investigated using Spearman Rank Order Correlation (see table 14). There was no relationship found between PSQI global score and posttraumatic stress symptoms ($p > .05$).

Table 14

Correlations between measures of sleep quality and health and posttraumatic stress symptoms in carers (N = 32 except where specified)

	Intrusion	**Avoidance**	**Hyperarousal**	**IES-R Total**
PSQI Global score	.28	.26	.29	.29
RAND-36 Subscales				
Physical functioning	-.20	-.31	-.43*	-.32
Role limitations due to physical problems	-.29	-.53**	-.45*	-.45**
Role limitations due to emotional problems	-.25	-.35	-.41*	-.34
Social functioning	-.36*	-.34	-.55**	-.43*
Emotional well-being[a]	-.51**	-.62**	-.67**	-.62**
Energy and vitality[a]	-.49**	-.56**	-.62**	-.58**
Pain[a]	-.37*	-.42*	-.38*	-.42*
General health	-.43*	-.55**	-.61**	-.56*

Note: high scores on the RAND-36 indicate better health
[a] $n = 31$
*$p < .05$, 2-tailed. ** $p < .005$, 2-tailed.

3.11 Phenomenology of Intrusions

3.11.1 Intrusive imagery

55% ($n = 17$) participants reported that they had experienced negative intrusive images and 52% ($n = 16$) reported that they had experienced intrusive images related to a past traumatic or upsetting event. 45% ($n = 14$) participants reported that they had experienced intrusive images related to their caring role and 39% ($n = 12$) reported experiencing intrusive images of feared outcomes associated with their caring role. 19% ($n = 6$) reported experiencing negative intrusive images in the previous week and 16%

(*n* = 5) in the previous month. Participants experiencing negative intrusive images either in the previous week or in the previous month either related or unrelated to the caring role (*n* = 11, 35%) completed the full intrusion interview. Only one intrusive image for each participant was explored in detail. If more than one negative intrusive image was experienced within the last month then the most upsetting image and/or the image related to the caring role was explored further. All of the participants who completed the intrusion interview (*n* = 11) reported at least one memory associated with their image. Table 15 gives a description of the negative intrusive images. It also details the memories, affect and encapsulated beliefs that the images elicited.

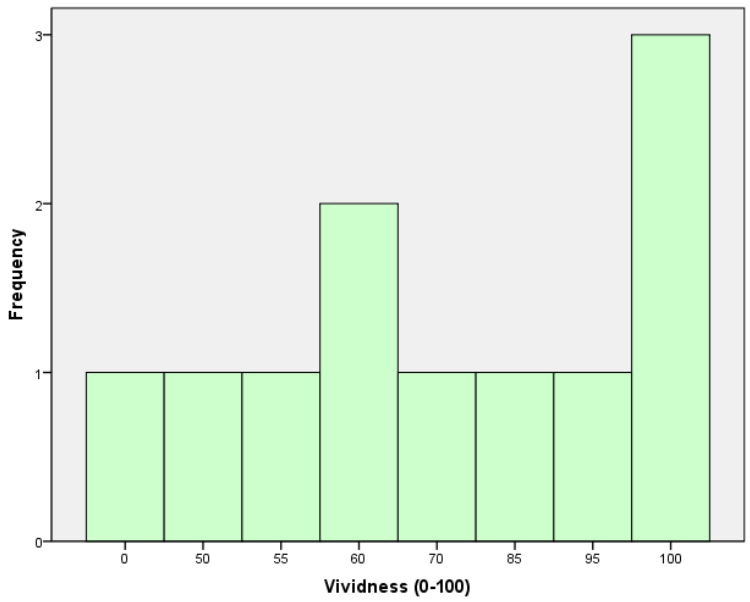
3.11.2 Content and other characteristics of the imagery

Table 15 gives a clear description of the content of participant's intrusive imagery. It is important to note that the interview process was very much guided by how comfortable the participants felt about talking about their experiences therefore there is some variability in the level of detail provided by participants.

Ten images related to the caring role and one related to childhood sexual abuse were described. Images were associated with the caring role in different ways, for instance, the impact of the illness on the relationships between younger children in the family and the cared for person, the mental health sectioning process and/or the involvement of police, diagnosis of schizophrenia and the death of the cared for person or their relative. The majority of intrusive images related directly to a stressful or traumatic event from the past (73%) and the remainder related to feared outcomes associated with the caring role (27%).

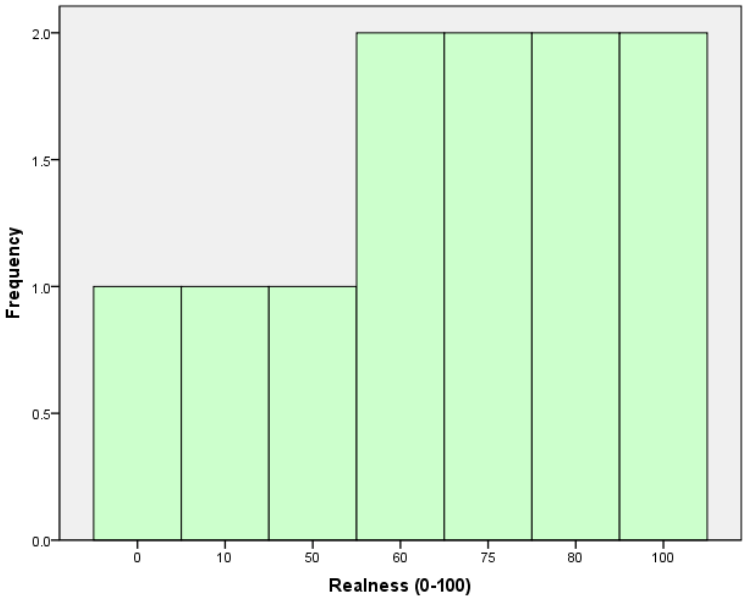
Across the 11 participants who completed the intrusion interview, there was variation in sensory experiences. All of the participants reported seeing a visual image. In terms of other sensory experiences: seven (64%) also experienced hearing sounds; four (36%) experienced associated smells; and 5 (46%) reported either tasting something or feeling something in their body. Participants were asked to rate the vividness of the image (0 = hazy image – 100 = most clear/vivid). The average rating of intensity for vividness was 70 (*SD* = 30.45, *n* = 11). Although the whole scale was used from 0-100, the data is positively skewed towards images being vivid, with almost all (*n* = 10, 91%) images being rated as 50 or higher in terms of vividness (Figure 2).

Figure 2. A graph showing vividness ratings for the image (*n* = 11)



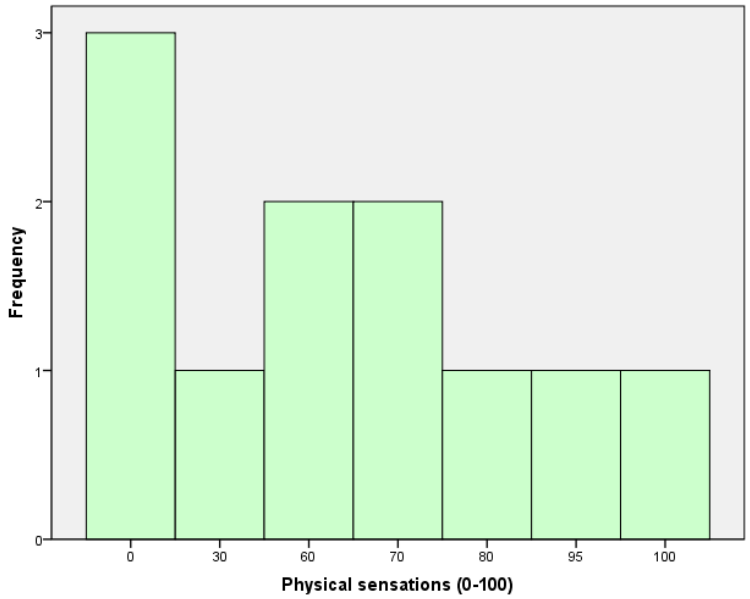
Participants were asked to rate how real the image felt (i.e., as if it was really happening; 0-100). The average rating of intensity for "realness" was 63 (*SD* = 32.51, *n* = 11). As can be seen in Figure 3, the data are positively skewed with the majority of images (*n* = 9, 82%) being rated as 50 or higher in terms of realness.

Figure 3. A graph showing level of realness of the image (*n* = 11)



Participants were asked if there were physical sensations associated with the image and asked to rate the intensity of these sensations (0-100). The average rating of intensity for physical sensations was 51 (*SD* = 37.82, *n* = 11). A rating of 0 in this instance reflected the absence of physical sensations. As shown in Figure 4, the majority of other participants (*n* = 7, 64%) rated the intensity of sensations as 60 or higher.

Figure 4. A graph showing the level of physical sensations associated with the image (*n* = 11)



3.11.3 Frequency and duration of imagery

Four participants (36%) experienced the image once or twice in the past week, two (18%) experienced the image several times a week, and five (46%) experienced the image at least once in the past month. For seven (22%) participants the intrusive image lasted for seconds, for two (6%) it lasted minutes, and for another two (6%) it lasted hours.

3.11.4 Emotions and distress associated with imagery

A variety of emotions were reported to be associated with the imagery. Based on participant's responses, the author grouped similar emotions together under the one label. For example, anxious, nervous or worried were grouped together under the label *anxiety*. As can be seen in Table 16, the highest rated emotions were sadness and fear, followed by anger, helplessness and shame. When reporting the associated emotion,

participants were asked to rate their emotion in terms of intensity (0-100). The majority of emotions were rated higher than 70 on this scale.

Table 16

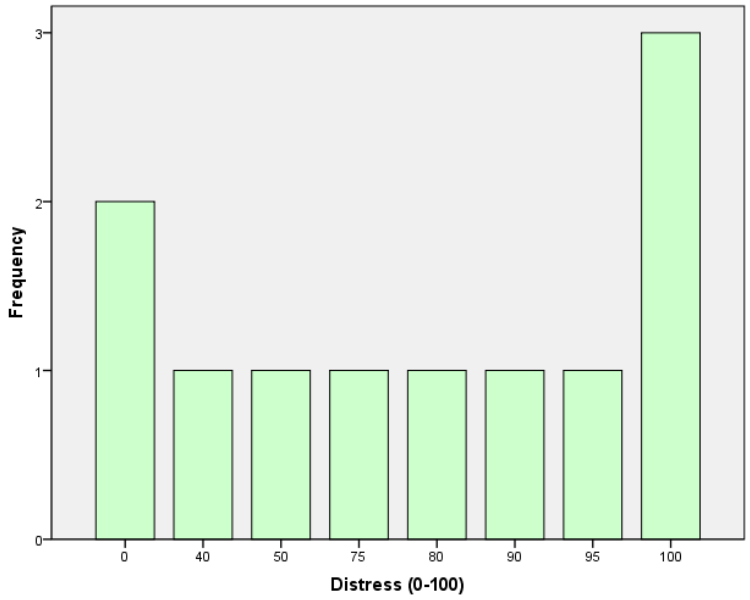
Different rates of emotion associated with imagery (n = 11)

Emotion	***n* (%)**	**Mean level of emotion rated from 0 - 100**
Sadness	5 (46%)	84
Fear	5 (46%)	74
Anger	4 (36%)	80
Helplessness	4 (36%)	85
Shock	3 (27%)	80
Shame	2 (18%)	72.5
Anxiety	1 (9%)	99
Overwhelmed	1 (9%)	70
Guilt	1 (9%)	75
Frustration	1 (9%)	70
Numb	1 (9%)	35
Hopelessness	1 (9%)	40

NB: most participants reported more than one emotion

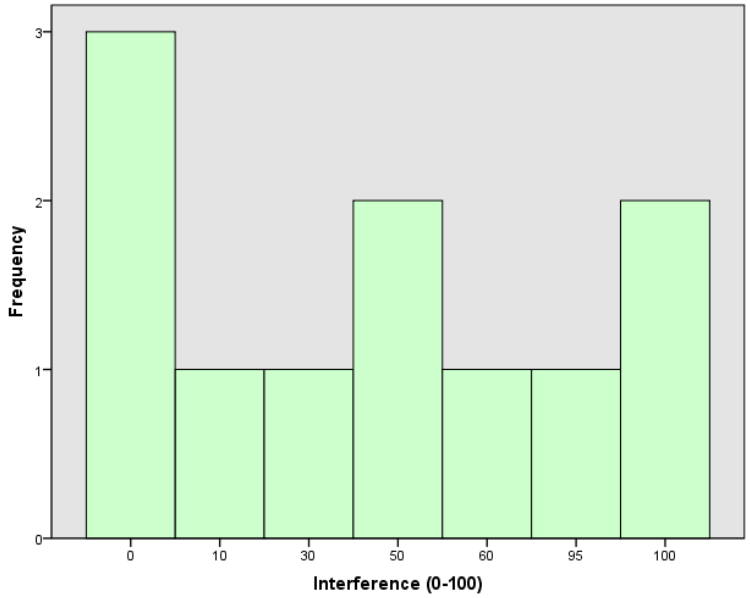
Of the 11 images that were described in more detail, the mean level of distress associated with the images was 66 out of 100 (*SD* = 38.48, *n* = 11). As can be seen in Figure 5, the data is positively skewed towards images being distressing with the majority (*n* = 8, 73%) being rated as 50 or higher in terms of distress and five of these being rated as extremely distressing (90 or higher).

Figure 5. A graph showing the distribution of distress associated with the imagery (*n* = 11)



The mean level of interference the image had on participants daily life was 45 (*SD* = 40.44, *n* = 11). As can be seen in Figure 6, five participants reported little or no interference on their daily life (rating 30 or lower) while three reported extreme interference (rating 95 or higher).

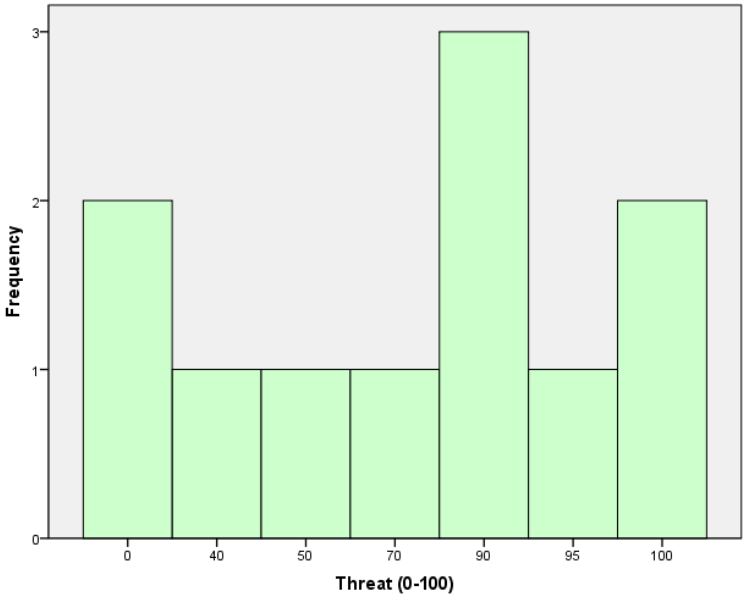
Figure 6. A graph showing the level of interference in daily life associated with the image (*n* = 11)



3.11.5 Subjective beliefs associated with imagery

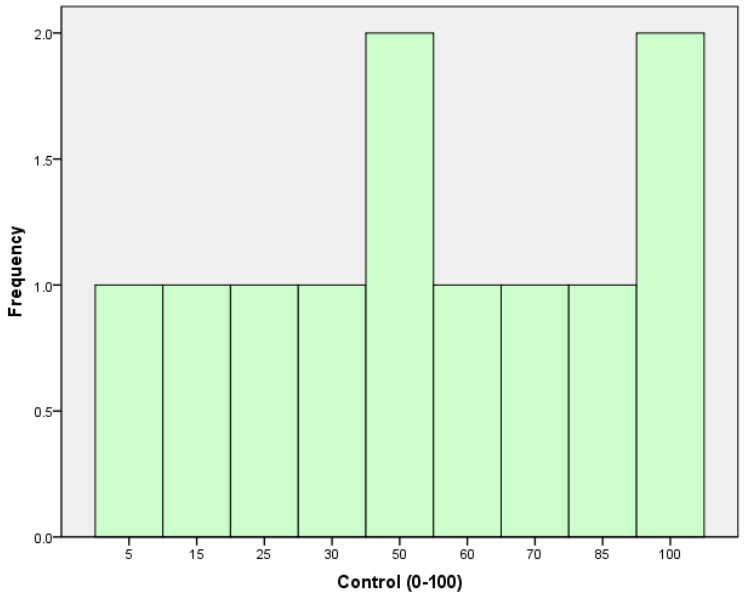
The mean level of threat associated with the 11 images reported was 66 (*SD* = 38.13, *n* = 11). As can be seen from Figure 7, over half of the images (*n* = 6, 55%) were rated as extremely threatening (rating of 90 or above).

Figure 7. A graph showing the distribution of threat associated with the imagery (*n* = 11)



The mean controllability that participants felt they had over the image was 54 (*SD* = 32.95, *n* = 11). As can be seen in Figure 8, all participants reported having some degree of control over their image (*n* = 11) and ratings were spread evenly across the entire range (range 5-100).

Figure 8. A graph showing the rate of perceived control over the imagery (*n* = 11)



3.11.6 Memories associated with the imagery

All of the participants for whom an image was explored in detail also had at least one memory associated with the image (*n* = 11). Only one memory that seemed to the participant to be most related to the image was explored in more detail. The average age of the participants in the memory was 31 (*SD* = 20.41, range 7-65), with almost half of the memories (*n* = 5, 45%) being before the age of 19. Details of memories are reported in Table 15. All of the memories related to past traumatic events and many were similar in content to the image. Those unrelated to the caring role included events such as childhood sexual abuse, rape, domestic violence, diagnosis of life threatening illness and witnessing death or accident of close family members. Memories related to the caring role were associated with the process of the service user being sectioned, police involvement, diagnosis (or realisation that service user was experiencing auditory hallucinations), the effect on other family members and seeing the service user acutely physically unwell (i.e., experiencing epileptic seizure). A variety of emotions were associated with the memory (see Table 17).

Table 17

Different rates of emotion associated with memory (n = 11)

Emotion	***n* (%)**	**Mean level of emotion rated from 0 - 100**
Sadness	7 (64%)	88
Anger	3 (27%)	90
Confusion	2 (18%)	85
Anxiety	2 (18%)	80
Fear	1 (9%)	75
Shame	1 (9%)	80
Sick	1 (9%)	80
Guilt	1 (9%)	70
Frustration	1 (9%)	100
Loneliness	1 (9%)	50
Numb	1 (9%)	100
Helplessness	1 (9%)	100
Hopelessness	1 (9%)	90
Worthlessness	1 (9%)	85

Note: most participants reported more than one emotion

In addition to rating how vivid the memory was, participants were also asked to rate the degree to which, when they had this memory, it felt as if the event was happening all over again and also whether the emotions and physical sensations were the same as, or very similar to, those that were felt in the actual event (see Table 18 for mean ratings).

Table 18

Mean rating for the degree of vividness, re-experiencing of the event, emotions and physical sensations (n = 11)

	M	***SD***	**Range**
Vividness	77	23.49	35-100
Re-experiencing event	38	35.24	0-90
Re-experiencing of emotions	44	35.69	0-90
Re-experiencing of physical sensations	36	37.30	0-90

Table 19 shows the mean level of distress, interference, controllability and threat associated with the images and memories.

Table 19

A comparison of mean levels of subjective experiences for intrusive imagery and memories (n = 11)

	Mean ratings for intrusive images (*SD*, range)	**Mean subjective ratings for associated memories (*SD*, range)**
Distress	66 (38.5, 0-100)	60 (34.9, 0-100)
Interference	45 (40.4, 0-100)	28 (32.3, 0-85)
Controllability	54 (32.9, 5-100)	56 (33.9, 0-100)
Threat	66 (38.1, 0-100)	53 (41.8, 0-100)

Table 15

A description of the intrusive image, affect, belief and associated memory (n = 11)

Gender	**Age**	**Description of Intrusive Image in past week or month**	**Associated Affect (SUDs rating from 0-100)**	**Encapsulated Belief (conviction in belief from 0-100)**	**Description of Associated Memory**
F	67	Son dead in his bed	1. Fear (75%)	1. I am fearful and won't be able to cope (100%)	1. Finding sister dead in her bed 2. Losing father when 7 years old and being sent away after his death
M	57	Sexual abuse as a child	1. Sad (75%) 2. Ashamed (50%)	1. I am vulnerable, other people are dangerous and the world is risky (75%)	1. Sexual abuse as child
F	63	Daughter after she was discharged from hospital, her granddaughter going to talk to her daughter and her daughter not responding	1. Sad (70%)	1. That's life (70%)	1. Daughter after she was discharged from hospital, her granddaughter going to talk to her daughter and her daughter not responding
F	27	Mother having epileptic seizure	1. Fear (90%) 2. Shock (100%)	1. I panic when I don't really need to (90%)	1. Mother having epileptic seizure
F	47	Self sitting in a wheelchair	1. Sad (80%) 2. Angry (100%) 3. Tearful (90%)	1. I am useless, people are not helpful and the world is selfish (60%)	1. Accident at work
M	49	Daughter hiding behind me scared of her mother	1. Sad (90%) 2. Angry (90%) 3. Helplessness (95%)	1. I must try to prevent it happening again, other people don't understand, this world has good things and sometimes bad and you never know what is going to happen in the next minute (90%)	1. Daughter hiding behind him scared of her mother
F	19	Mother being forced to go into hospital	1. Numb (35%)	1. My mum is not well; she's not like other mum's and I'm not like other daughters; motivates me to do well so that I'm comfortable when I'm older, so I'm not feeling stress that would push me over the edge (85%)	1. Mother forced to go into hospital

Table 15

A description of the intrusive image, affect, belief and associated memory (n = 11; continued)

Gender	Age	Description of Intrusive Image in past week or month	Associated Affect (SUDs rating from 0-100)	Encapsulated Belief (conviction in belief from 0-100)	Description of Associated Memory
F	45	Deceased body of partners brother	1. Sad (90%) 2. Angry (70%) 3. Guilty (75%) 4. Frustrated (70%)	1. The world can be really awful (100%)	1. Having to identify the deceased body of partner's brother 2. Grandmother's funeral
F	51	Police officers standing at the bed	1. Fear (85%) 2. Shock (90%) 3. Worried (99%) 4. Shame (95%) 5. Humiliation (95%) 6. Powerless (95%)	1. I've failed. There must have been something else I could have done (95%) 2. It tells me how powerless I am and about my position in society: either I am really low down or perhaps I was used as an example (65%) 3. We live in a hierarchical and sexist society (100%) 4. The world is a brutal place (95%)	1. Partner being sectioned with police involvement 2. Being raped by undercover policeman 3. Sexual abuse as child
F	52	Son standing frightened in presence of police	1. Sad (100%) 2. Fear (80%) 3. Powerless (100%)	1. It's going to be a forever thing (100%) 2. It's my responsibility; he's not going to get better; I'm always going to be worrying (100%) 3. Fear my son can't be the only one, there must be quite a few people out there like that (100%) 4. The world is a scary place (100%)	1. The night her son said 'I wasn't talking to you' (the night when she realised her son was hearing voices)
F	52	Son coming home and disclosing diagnosis of schizophrenia	1. Angry (60%) 2. Helpless (50%) 3. Fear (40%) 4. Shock (50%) 5. Hopeless (40%)	1. Represents being out of control, vulnerable, life can change in seconds (90%) 2. I am a frail human being (60%) 3. They don't always know what is best for you - he didn't protect himself (60%) 4. Have to protect yourself (70%)	1. Son coming home after receiving diagnosis 2. Father being knocked over by car 3. Brother being violent 4. Mother dying 5. First being diagnosed with cancer

Note: the first memory listed for each participant is the memory that was explored in detail

4 Discussion

The current study sought to explore posttraumatic stress symptoms in a sample of carers of people with psychosis, including intrusive imagery, and to examine the relationship between posttraumatic stress symptoms, well-being and caregiving experiences. This section includes a summary of the main findings, a discussion of how the results compare to existing research, the theoretical and clinical implications of the results, and the strengths and limitations of the study. It ends with suggestions for further research and conclusions drawn from the study.

4.1 Summary of Main Results

The sample included 32 carers of people with psychosis aged between 19 and 83 years. Most carers were female and the majority identified as either White or Black/Black British. The average duration of the caregiving relationship was approximately 8 years (range: 2 months to 30 years). The carers were mainly the parents of the service user (59%). Most participants lived with the service user; and for half of the participants, the service user was their son.

Almost half of the sample (44%) reported symptoms of traumatic stress on the IES-R, but only one participant (3%) met full diagnostic criteria for PTSD in response to an event related to their caring role. Carers indicated they had experienced or witnessed a range of stressful life events related to their caregiving role and the majority (77%) also reported experiencing or witnessing traumatic events unrelated to their caring role. As predicted, posttraumatic stress symptoms were positively related to negative appraisals of caregiving, in particular illness related stigma, problems with services and effects of the illness on family. These correlations were observed between negative appraisals of

caregiving and an overall rating of posttraumatic stress symptoms as well as across all three PTSD symptom clusters (i.e., intrusions, avoidance, and hyperarousal).

In relation to trauma appraisals, negative cognitions about the self and self-blame for the trauma were strongly associated with greater levels of posttraumatic stress symptoms. However, negative cognitions about the world were only moderately correlated with hyperarsousal symptoms. As predicted, positive correlations were found between posttraumatic stress symptoms and levels of distress, anxiety, and depression. Positive correlations were also found between posttraumatic stress symptoms and avoidant coping style but not with levels of social support. Contrary to predictions there were no associations between posttraumatic stress symptoms and expressed emotion. Greater levels of posttraumatic stress symptoms were associated with general health status, role limitations due to physical problems and pain, but not overall physical health functioning. Contrary to predictions, there were no correlations found between posttraumatic stress symptoms and the levels and quality of sleep.

Almost half of the sample (44%) reported that they had experienced negative intrusive images related to their caring role. The most distressing image and/or the one related to the caring role for each participant, if it had occurred at least once during the past month, was also explored in more detail (n = 11; 35%). All the images explored in detail in this study, with the exception of one, were related to the caring role. Typically, the images were appraised as vivid, moderately to extremely distressing, and invoked strong negative emotions. Many images elicited strongly held negative beliefs about the self, others or the world. All of the participants for whom an intrusive image was explored in detail, reported experiencing a memory associated with the image. Almost

half of the memories were from childhood and all memories related to stressful or traumatic life events.

4.2 Comparison of the Results with Existing Research

4.2.1 Posttraumatic stress symptoms in carers of people with psychosis

The level of posttraumatic stress symptoms found in this sample are consistent with figures reported in other studies measuring posttraumatic stress symptoms in carers of people with psychosis (Barton & Jackson, 2008; Loughland et al., 2009). The types of carer related events reported as traumatic have also been identified in previous studies with carers of people with psychosis, for example aggression (Ferriter & Hubband, 2003; Loughland et al., 2009) and risk of suicide (Struening et al., 2001). Of interest was the high rate of previous trauma reported by carers that was unrelated to the caring role and this needs to be considered when interpreting the results especially in relation to self-report measures of posttraumatic stress symptoms. Although, it should be noted that these events were identified in response to an open ended question and not assessed to determine if they meet current diagnostic definitions of traumatic events (i.e., Criterion A on the SCID PTSD module). Given the overall lifetime prevalence rates of exposure to traumatic events in the general population (89.6%; Breslau et al., 1998), it is conceivable that a significant proportion of the current sample would also be expected to report a history of these experiences.

Only one carer in this study was found to meet criteria for PTSD, based on data drawn from a structured clinical interview. There are no known previous studies using a formal diagnostic interview to assess PTSD in carers of people with psychosis. The 3% prevalence rate for PTSD in response to events related to caring for someone with psychosis is slightly lower than figures published in studies using formal structured

clinical interviews with other clinical groups; for example, parents of children with life threatening physical illnesses (7%, Stoppelbein & Greening, 2007; 6.2%, Manne, Hamel, Gallelli, Sorgen, & Redd, 1998; 13.7%, Kazak et al., 2004) and mothers of children undergoing bone marrow transplantation (7.8%; Manne et al., 2002). The current 3% figure is also lower than the risk of PTSD following exposure to trauma in general population studies (9.2%; Breslau et al., 1998). However, the sample size is likely to be too small to reliably estimate prevalence rates in this population; further studies with larger sample sizes would be indicated. Moreover, the percentage rate obtained in the current study only represents the presence of PTSD in relation to traumatic events related to the caring role.

In contrast, more than one-third of the sample (44%) reported symptoms indicative of a diagnosis of PTSD based on the self-report measure using the Creamer et al. (2003) criterion (IES-R > 1.5). The discrepancy between self-reported posttraumatic stress symptoms and those identified by the diagnostic interview is not unexpected but does indicate methodological issues that might have influenced the rates found. It is well-documented that the use of self-report questionnaires can lead to over-reporting of trauma like symptoms. The different rates using the SCID and the IES-R are consistent with similar discrepancies noted between the SCID and other self-report measures assessing posttraumatic stress symptoms (PCL-C; Stoppelbein & Greening, 2007; Manne et al., 1998). This is partially within the context of the trauma event needing to meet particular criteria if a diagnosis of PTSD is to be allocated (i.e., Criterion A). Unlike the SCID PTSD module, the self-report measure used in this study did not screen out those carers for whom the traumatic event did not meet this criterion. Furthermore, the IES-R was not designed to make a categorical diagnosis and a disadvantage of the measure is that the items are not directly tied to DSM diagnostic

criteria, making comparisons difficult (Creamer et al., 2003). The current findings indicate that a significant number of false positives would result if the suggested cut-off for the self-report measure was used to report PTSD in this sample. On the basis of the psychological models of stress and coping (Szmukler et al., 1996; Mackay & Packenham, 2011) and previous research regarding the experiences of caregivers in psychosis, it makes sense that a portion of caregivers would have distinct and identifiable patterns of posttraumatic stress symptoms but would not necessarily meet criteria for PTSD.

The results suggest that it is possible that the current operational definitions of PTSD may not be meaningfully applied to carers of people with psychosis when identifying and addressing troubling posttraumatic stress symptoms. It is possible that carers of people with psychosis have different problems characterised by chronic stress and ongoing traumatic life events, rather than formal PTSD diagnoses. This would certainly be supported by the observation that many carers in this study, despite identifying numerous stressful life events related to the caring role, were unable to identify one event in particular that stood out from the others. Although the number of carers who met full PTSD criteria related to their caring role was very low, posttraumatic stress symptoms overall were relatively high. This is an important phenomenon to assess clinically because "subthreshold" PTSD has been associated with social and occupational impairment comparable to full PTSD (Stein, Walker, Hazen, & Forde, 1997). From a classification point of view, the posttraumatic stress symptoms (in particular the severity of the stressor) may not be indicative of a diagnosis of PTSD as currently defined DSM-IV-TR. However, the presence of intrusions, avoidance, and arousal does suggest a clinically significant stress response (Boye & Malt, 2002). Some carers may fulfil the criteria for a chronic adjustment disorder, specified as chronic

when the duration of the disturbance is longer than 6 months in response to a chronic stressor or to a stressor that has enduring consequences (American Psychiatric Association, 2000).

Carek et al. (2010) in reference to the cognitive model of PTSD (Ehlers & Clark, 2000) outlines a number of ways that chronic stressors may contribute to the severity of posttraumatic stress symptoms in carers of stroke survivors, which could also be meaningfully applied to carers of people with psychosis. First, the experience of an ongoing stressor may impede the caregiver's ability to fully process (or come to terms with) his or her acute reactions to the first episode of psychosis or other initial trauma related to the illness and/or caring role, which is consistent with the idea that disturbances in autobiographical memory constitute a risk factor for the development and persistence of posttraumatic stress symptoms. Second, the negative effects of the ongoing stressors may be perceived to be indicative of a permanent negative change in the caregiver's life, consistent with the idea that negative appraisals of the sequelae of the trauma event may serve to maintain PTSD. Third, the experience of chronic stressors may evoke reminders of the illness and the caring role that may, more directly, act as triggering cues for intrusive re-experiencing. The associations found in this study between negative caregiving appraisals and posttraumatic stress symptoms offer some support for the application of this explanation to carers of people with psychosis.

4.2.2 Posttraumatic stress symptoms and negative caregiving appraisals in carers of people with psychosis

The results provide support for the relationship between posttraumatic stress symptoms in carers of people with psychosis and negative appraisals of caregiving experiences. Posttraumatic stress symptoms were associated with negative appraisals of caregiving;

relationships were most consistently found with appraisals of stigma followed by appraisals about the effects on family and problems with services. The hyperarousal symptom cluster in particular was related to all negative caregiving experiences.

This is the first study to investigate the relationship between these variables in carers of people with psychosis. However, the results are consistent with research linking high levels of psychological distress and negative appraisals of caregiving (Onwumere et al., 2008; Addington et al., 2003; Harvey et al., 2001). The current results provide further support for the application of the stress, appraisal, and coping (SAC) framework to caregiving experiences in psychosis (Szmukler et al., 1996; Mackay & Pakenham, 2011) and cognitive models of caregiving (Kuipers et al., 2010) specifically that carers make appraisals about the illness and that these appraisals influence their psychological well-being. Larger effects sizes were observed for relationships between posttraumatic stress symptoms and stigma and effects on family, implying that these appraisals in particular may have an important role in either the onset and/or maintenance of posttraumatic stress symptoms in carers of people with psychosis. Perhaps for carers of people with psychosis, stigma and effects on family can be perceived as particularly threatening and harmful. However, the direction of the relationships between appraisals of caregiving and posttraumatic stress symptoms cannot be assumed given the cross-sectional design and research employing a prospective design is required to further clarify these relationships.

4.2.3 Posttraumatic stress symptoms and trauma appraisals in carers of people with psychosis

Posttraumatic stress symptoms were strongly related to negative cognitions about the self and self-blame for trauma related to the caring role. These findings broadly mirror

those found in other studies with caregivers of stroke survivors (Carek et al., 2012) and parents of children with Type 1 Diabetes (Horsch et al., 2012). However, unlike these studies, the current study found that negative cognitions about the world were only related to the hyperarousal symptom cluster, not overall posttraumatic stress symptoms or the avoidance and intrusion symptom clusters. Furthermore, this relationship needs to be interpreted with caution, given the study was underpowered to correct for multiple comparisons and this correlation was significant at $p < .05$ and not $p < .01$. The finding that self-blame for the trauma was strongly associated with posttraumatic stress symptoms is consistent with previous research with carers of people with psychosis. Fortune et al. (2005) reported that carer distress was associated with coping styles characterised by self-blame and Barrowclough et al. (1996) found that carers who made self-blaming attributions experienced higher levels of distress. Finally, the findings are consistent with recent cognitive models of PTSD (Ehlers & Clark, 2000), which postulate that negative appraisals about the trauma and its sequelae play a role in the onset and maintenance of posttraumatic stress symptoms.

It seems that in carers of people with psychosis, self-blame for the trauma and negative cognitions about the self tend to play more of a role in the onset and maintenance of posttraumatic stress symptoms than negative cognitions about the world. It is possible that carers may feel in some way responsible for the negative outcomes associated with psychosis, for instance, not being able to: alleviate stressors triggering the psychosis; identify the early symptoms of psychosis; or minimise the negative impact of the illness on other family members, for example, younger siblings of the service user. In contrast, it seems carers with posttraumatic stress symptoms do not appraise stressful life events related to their caring role to mean that the world and other people in general are dangerous, unpredictable, or cannot be trusted or relied upon. This result is likely to

reflect that traumatic events or stressful life events related to the caring role may be more predictable and involve people that are known to the carer, compared to other traumatic events such as natural disasters, accidents, or violence/abuse from strangers.

4.2.4 Posttraumatic stress symptoms, avoidant coping and social support in carers of people with psychosis

Strong relationships were found between avoidant coping and posttraumatic stress symptoms. This is consistent with a substantial body of research supporting an association between avoidant coping and distress in people with psychosis (Scazufca & Kuipers, 1999; Raune, et al., 2004; Onwumere et al., 2011; Mackay & Pakenham, 2011; Magliano et al., 2000). Furthermore, similar associations between avoidant coping and posttraumatic stress symptoms have also been found in informal carers following life threatening illness (Noble & Schenk, 2008). The findings are also consistent with theoretical models of stress and coping (Lazarus & Folkman, 1984; Ehlers & Clark, 2000) highlighting the role of maladaptive coping strategies in the onset and maintenance of posttraumatic stress symptoms.

The prediction that social support would be negatively associated with posttraumatic stress symptoms was not supported in the current study. This is inconsistent with previous reports highlighting social support as a protective factor with regard to the development of PTSD (e.g., Brewin, Andrews, & Valentine, 2000) as well as assuming an important relationship to effective coping (Joyce et al., 2003) and better health and higher life satisfaction (Mackay & Peckenham, 2011) in carers of people with psychosis. However, the finding needs be interpreted cautiously because of the nature of the measure used to assess social support in this study. A single question, the confidante question, was used as a measure of carer social support. All carers in this study

endorsed this item, a result similar to previous research using this item which found the majority of carer endorsed the item (80%; Onwumere et al., 2009). The confidante question was chosen in this study as part of an overall attempt to use assessments that were valid but brief so that participant fatigue could be avoided. However, it is likely that the presence or absence of a confidante is insufficient to elucidate the relationship between posttraumatic stress symptoms and social support. A measure of the dimensional components of support such as frequency and quality and the different sources (e.g., Multi-Dimensional Support Scale; Winefield, Winefield, & Tiggemann, 1992), may have yielded different results.

4.2.5 Posttraumatic stress symptoms and distress in carers of people with psychosis

This study found support for relationships between posttraumatic stress symptoms and distress, depression, and anxiety. This is largely consistent with Boye and Malt's (2002) finding that intrusion and avoidance was correlated with distress in carers of people with psychosis. It is likely that some of the association between posttraumatic stress symptoms and distress is due to the overlap in symptoms measured by the questionnaires. In particular, the correlation with anxiety is to be expected, however, the relationship with depression highlights the possibility co-morbidity of posttraumatic stress symptoms and depression in this population. Overall, the results suggest that posttraumatic stress symptoms could be contributing to overall distress experienced by carers of people with psychosis including depression.

4.2.6 Posttraumatic stress symptoms and expressed emotion in carers of people with psychosis

It was hypothesised that greater posttraumatic stress symptoms would be related to high expressed emotion in carers of people with psychosis, however the results failed to

support the existence of such a relationship. Although there has been a lack of previous research in this area, the hypothesis was guided by the literature (e.g., Hall et al., 2006; Boye et al., 1998). The absence of a significant effect was surprising given that high EE has been conceptualised as an adaptive coping strategy and an attempt to reduce the perceived stressfulness of the caring role (Raune et al., 2004). Furthermore, previous research has tended to report a positive association between high EE and distress in caregivers of people with psychosis (e.g., Kuipers et al., 2006). More specifically, Boye and colleagues (1998) found that carers of people with psychosis with high EOI had higher scores on measures of intrusions and psychophysiological activation than carers with consistently low EOI levels. Previous research with carers of people with psychosis has also demonstrated strong positive relationships between high EE and the effect of stigma on family members (Phillips et al., 2002), avoidant coping (Raune et al., 2004), and self-blame (Leff & Vaughn, 1985; Bentsen et al., 1998; Peterson & Docherty, 2004); with self-blame also implicated in the onset and maintenance of PTSD (Ehlers & Clark, 2000). Furthermore, it was hypothesised that avoidance associated with overprotection may create conflict. Hall et al. (2006) found in a sample of parents of children with acute burns, that parental-child conflict was associated with posttraumatic stress symptoms in parents.

The failure to identify a relationship between high EE and posttraumatic stress in this sample of carers of people with psychosis may be explained by different factors. First, there are some differences between the current study and previous research supporting an association between high EE and posttraumatic stress symptoms. For example, Boye et al. (1998) combined items from a measure designed to measure general distress rather than using a scale designed to measure posttraumatic stress symptoms in particular, so it is possible that the results they obtained provide further evidence for the association

between expressed emotion and distress, rather than expressed emotion and posttraumatic stress symptoms. Furthermore, most studies finding a relationship between high EE and distress, including the Boye et al. (1998) study, used the Camberwell Family Interview (CFI; Leff & Vaughn, 1985) rather than the FMSS (Magana et al., 1986) (e.g., Kuipers et al., 2006). Studies that have compared the FMSS with the Camberwell Family Interview (CFI; Vaughn & Leff, 1976) indicate that the FMSS may underestimate the CFI score by 20% to 30%. This suggests that a high EE rating on the FMSS is likely to indicate a high EE rating on the CFI, while a low EE rating on the FMSS does not necessarily correlate with a low rating on the CFI (Leeb et al., 1991; Magana et al., 1986). When reviewing measures of EE, Hooley and Parker (2006) also highlighted that relative to the "gold standard" CFI, the FMSS tends to under-rate the occurrence of high EE. Hooley and Parker (2006) argue that when researchers fail to find an association between FMSS-rated EE and any given outcome, the chance that such a negative finding represents a Type II error is much more of a concern than it would have been if the researchers had used the CFI. This limitation of the FMSS should be considered when interpreting the results. Care also needs to be taken when comparing the current FMSS-generated results with those that use the CFI because of the great differences in source material (Wearden et al., 2000).

4.2.7 Posttraumatic stress symptoms, physical health and sleep in carers of people with psychosis

Greater levels of posttraumatic stress symptoms were associated with some aspects of physical health, specifically general health, role limitations due to physical problems and pain, but not physical functioning. Physical health has been associated with caregiving burden in carers of people with psychosis (Gutierrez-Maldonado et al., 2005; Perlick et al., 2005). In combination, these results suggests that posttraumatic stress

symptoms may be impacting on physical health associated with the caring role in psychosis, however, it would be premature to draw any firm conclusions about causal processes; further research is required employing a prospective design.

Contrary to hypotheses, sleep quality was not associated with posttraumatic stress symptoms. Sleep disruption has been associated with anxiety in several caregiver groups and has been found to mediate the relationship between caregiver burden and anxiety (Phillips et al., 2009). Furthermore, sleep difficulties have commonly been reported among individuals with PTSD (Ohayon & Shapiro, 2000) and are believed to play a role in the development of PTSD (Harvey & Bryant, 1998). Sleep difficulties, such as nightmares and insomnia are key characteristics of PTSD. It is possible that the associations found between anxiety and sleep disturbance in other caregiver groups (e.g., Phillips et al., 2009) is partly due to study samples containing a high number of carer groups where the care recipient is characterised by frequent nocturnal awakenings, such as in dementia.

4.2.8 Intrusive imagery in carers of people with psychosis

The rate of intrusive imagery related to the caring role experienced within the previous month (35%) was less than that reported in studies of depression (44%, Patel et al., 2007; 45%, Gregory et al., 2010) or PTSD (75%; Michael, Ehlers, Halligan, & Clark, 2005). It should be noted however that there were methodological differences in how intrusions were defined and elicited in these studies therefore comparisons should be interpreted cautiously.

The majority of intrusive images reported by carers related to actual stressful or traumatic events from the past (73%) and the remainder related to feared outcomes

associated with the caring role (27%). This is similar to Gregory et al. (2010) finding that depression was associated with intrusive memories of negative experiences, but also with vivid and distressing future-focussed images. For the intrusive images directly associated with a past stressful life event, the image tended to represent a "snapshot" from the original memory and related to the moments with the largest emotional impact. It is possible that some of the images were similar to the worst moments or "hotspots" reported as intruding in PTSD (Grey, Young, & Holmes, 2002; Holmes, Grey, & Young, 2005).

The content of images highlighted several themes related to the caring role, for instance, the impact of the illness on the relationships between younger children in the family and the service user, the sectioning process and/or the police involvement in the pathway to treatment, receiving a diagnosis of schizophrenia, and the death of the cared for person. Several of these themes are similar to those identified in people with depression, namely interpersonal problems, injury, illness, or death (Gregory et al., 2010; Patel et al., 2007). However, the findings also identify images related to specific caregiving experiences in psychosis, for example, police involvement in the pathway to treatment and the stigma and feelings of loss that can be associated with a diagnosis of schizophrenia. This provides some support for the finding that the content and meaning associated with intrusive images tend to vary according to individual concerns and frequently correspond with concerns of a given diagnostic group (Holmes & Mathews, 2010).

On average, intrusive images were rated high in terms of distress, similar to levels of distress associated with intrusive images in PTSD (Speckens, Ehlers, Hackman, & Clark, 2006). This is particularly relevant given that distress caused by intrusive memories has been found to be a consistent predictor of PTSD severity (e.g., Michael et

al., 2005; Ehlers & Steil, 1995). In the current sample, the predominant emotions associated with the intrusive images were sadness, fear, anger and helplessness; three of which are very close to those emotions strongly endorsed for images experienced in depression (sadness, helplessness and anger; Gregory et al., 2010; Patel et al., 2007) and the endorsement of fear suggests emotions similar to those experienced in people with PTSD.

On average, carers tended to endorse relatively high ratings of vividness as well as the sense that the image was real or happening now rather than something from the past, and these ratings were similar to those found in people with PTSD (Speckens et al., 2006). Intrusive images were also given relatively high ratings in terms of threat. It has been suggested that the subjective sense of "nowness" appears to be a general characteristic of trauma memories and that this creates a sense of threat associated with the intrusive images (Ehlers & Clark, 2000). Patel et al. (2007) also found re-experiencing symptoms in people with depression, suggesting that this phenomenon is not confined to PTSD. In contrast to previous studies in depression (Patel et al., 2007), on average intrusive images were experienced as only moderately uncontrollable and interfering in daily life.

All participants, for whom an intrusive image was explored in detail, had at least one memory associated with the image. All memories related to past traumatic events of which many were similar in content to the image. Sadness was the most comment emotion associated with the memories, followed by anger, confusion, and anxiety. On average, associated memories were rated relatively high in terms of vividness but much lower in terms of the degree to which it felt as if the event was happening all over again and also whether the emotions and physical sensations were the same as, or similar to,

the actual event. Although associated memories were, on average, given similar ratings of distress and controllability to the intrusive images, they were rated lower on interference and threat. The fact several participants listed multiple memories associated with the intrusive image, suggests that sometimes intrusions may form part of a network of related representations in memory (Patel et al., 2007). These representations may also be highly accessible and may share similar meanings and/or underlying core beliefs about the self and/or their future, as found intrusions in people with depression (Patel et al., 2007).

4.3 Theoretical Implications

Overall, the findings lend support for the application of a stress and coping framework to better understand posttraumatic stress symptoms and distress in a sample of carers of people with psychosis. The associations between posttraumatic stress symptoms, negative caregiving appraisals and avoidant coping lend support to the stress, appraisal, and coping framework (SAC; Lazarus & Folkman, 1984) and cognitive models of caregiving (Kuipers et al., 2010). Specifically, carers make appraisals about the impact of the illness, and these appraisals then interact with coping ability to determine their psychological well-being and distress (Mackay & Peckenham, 2011; Szmuckler et al., 1996). Other factors, such as social support are believed to have the potential to modify appraisals and coping ability and therefore outcome (Mackay & Peckenham, 2011; Szmukler et al., 1996). The finding that all carers had someone in whom they could confide draws this later point into question however the methodological limitations associated with the social support measure used in this current study (as discussed above) prevent conclusions being drawn regarding the associations between social support and posttraumatic stress in this sample.

This study also provides support for the role of negative appraisals and dysfunctional coping strategies in the maintenance of PTSD, as outlined by Ehlers and Clark's (2000) cognitive model. Specifically, relationships were found between posttraumatic stress symptoms and negative appraisals of trauma, as well as avoidant coping. It is possible that negative appraisals about specific traumatic events related to the caring role, may be maintaining posttraumatic stress symptoms in carers of people with psychosis. Furthermore, according to the cognitive model of PTSD (Ehlers and Clark, 2000), it is possible that negative appraisals of specific traumatic events related to the caring role, such as negative cognitions about the self and self-blame for the trauma, may lead individuals to engage in avoidant coping strategies, such as thought suppression (e.g., trying to push thoughts about the event from their mind), that, paradoxically, may actually increase and maintain posttraumatic stress symptoms.

Some caution needs to be taken when interpreting the results in relation to the theoretical models discussed above because all variables were measured at the same time and thus causal relationships cannot be assumed. It is possible, for example, that avoidant coping strategies are a symptom of posttraumatic stress rather than a factor related to the onset and maintenance of posttraumatic stress symptoms, especially since avoidance behaviours form part of the avoidance symptom cluster of posttraumatic stress symptoms. However, evidence from studies which measured individuals coping skills prior to a trauma have shown that preferences for maladaptive coping prior to the traumatic event are predictive of subsequent PTSD rather than a consequence of PTSD (Gil, 2005; Eid, 2003).

Holmes and Mathews (2010) outline how imagery can influence and maintain a person's emotions, behaviours and beliefs about the self and world. Application of this

theoretical framework to carers of people with psychosis suggests how intrusive imagery may influence and maintain distress including posttraumatic stress symptoms and depression. The findings from the study reported here provide some support for this framework, suggesting that intrusive imagery can maintain negative emotions, behaviours and beliefs about the self and the world in carers of people with psychosis. In particular, carers in this study reported distressing intrusive images related to their caring role and associated negative meanings to these images. Furthermore, negative appraisals of both caregiving experiences and the trauma related to the caring role, were found to be related to posttraumatic stress symptoms. Avoidant coping strategies were also related to posttraumatic stress symptoms. It could be hypothesised that both negative appraisals and avoidant coping strategies maintain intrusive imagery and posttraumatic stress symptoms in general. In addition, the meanings associated with the intrusive images and associated memories are likely to affect subsequent cognitive, emotional, behavioural and physiological activation and therefore play an important role in the experience of caregiving. Future research is needed to determine if intrusive images in carers of people with psychosis maintain posttraumatic stress symptoms.

4.4 Strengths and Limitations

The strengths of the study include the use of well-established theory to guide the research and reliance on psychometrically sound measures. It has advantages over previous studies investigating posttraumatic stress symptoms in carers of people with psychosis, in demonstrating associations between posttraumatic stress symptoms and cognitive factors and avoidant coping style. The study also used both self-report and structured clinical interview in the measurement of the posttraumatic stress symptoms. Despite these strengths, there are a number of limitations to consider.

4.4.1 Sample

The sample was self-selecting and the study did not systematically evaluate reasons why some carers declined to participant, therefore sample bias is possible, and the study is not likely to be representative of carers of people with psychosis in general. This has implications for the accuracy of the estimated frequency of posttraumatic stress symptoms and intrusive imagery in carers. For instance, carers with more severe posttraumatic stress symptoms may have been more likely to respond (i.e., help seeking), or equally may have wanted to avoid reminders of their experiences and therefore been less likely to respond. There was also relatively high numbers of carers for whom English was not their first language, reflecting the inner city population from which the sample was recruited, and the relatively high incidence of psychosis in particular black and minority ethnic groups (Fearon et al., 2006). Future studies would benefit from samples recruited from rural and urban areas, and an evaluation of the reasons for non-participation. The majority of carers in this study had also been caring for longer than two years (n = 24; 75%) with an average duration of approximately eight years. There is strong evidence to suggest a higher risk of distress in family members of individuals with first episode psychosis compared to family members of individuals with a longer course of illness (Martens & Addington, 2001). However, the cumulative effect of multiple traumatic events also suggests longer duration of caregiving may be associated with greater posttraumatic stress symptoms. Future research is needed to determine the significance of duration of caregiving on posttraumatic stress symptoms.

The difficulties associated with recruitment, especially within the time-frame of the study, including a low response rate (18% of all of those initially approached), resulted in a relatively small sample. To a degree this is to be expected within this population, where demands on time and levels of stress are high. However, the study was

underpowered to correct for multiple testing, with the possibility of a Type-I error, meaning results should be interpreted with caution. Furthermore, it was also not possible to explore the influence of mediating and moderating variables, which would have offered important information about the ability of theoretical models (e.g., SAC, Lazarus & Folkman, 1984; Cognitive model of PTSD, Ehlers & Clark, 2000), to explain the onset and maintenance of posttraumatic stress symptoms in this population. However, the fact that all the predictions were based upon a priori hypotheses driven by previous research and/or theoretical models and the use of non-parametric analyses throughout, suggests that findings even at a <.05 level can be considered relatively robust and ignoring these findings completely may equally lead to Type II errors.

4.4.2 Design

The cross-sectional design of the study limits the conclusions that can be drawn, from associated variables, regarding causality. For instance, as previously mentioned, it may be the case that the experience of posttraumatic stress symptoms results in excessively negative appraisals about the caring role and its sequelae, rather than negative appraisals determining posttraumatic stress symptoms as proposed by cognitive models of PTSD (Ehlers & Clark, 2000). Prospective, longitudinal studies are required to assess the direction of the relationships between variables and to confirm the role that these variables, for example, cognitive factors and avoidant coping strategies, play in the development of posttraumatic stress symptoms in carers of people with psychosis. Furthermore, the current study lacked a comparison group of carers of people without psychosis therefore it is uncertain to what degree the current observations are associated with the caring role in general as opposed to caring for a person with psychosis. The absence of a control or comparison group also means conclusions cannot be drawn about the similarities and differences between intrusive images in carers of people with

psychosis, compared with other caregiving groups, groups with particular clinical disorders or the general population. However, the aim of the study was to explore characteristics and factors associated with posttraumatic stress symptoms in a particular carer group; therefore, this lack of comparison should have a minimal impact on current observations and recommendations in relation to this population.

4.4.3 Measures

The Impact of Event Scale – Revised (IES-R; Weiss & Marmar, 1997) was chosen as a measure of posttraumatic stress symptoms to allow comparison of results with existing research exploring posttraumatic stress symptoms in carers of people with psychosis (Barton & Jackson, 2008; Boye & Malt, 2002; Loughland et al., 2009). However, there are some limitations with the measure that are inherent in many measures of PTSD. The IES-R (Weiss & Marmar, 1997) can be tailored to any specific life event. In the current study, participants who identified a specific traumatic event related to the caring role during the administration of the adapted SCID module were instructed to complete the IES-R in relation to this event. All other carers were asked to complete the questionnaire in relation to the caring role in general. Carers who completed the measure related to the caring role in general, identified several stressful events related to the caring role but could not identify one specific event as being the most upsetting or traumatic. Asking carers to rate the questionnaire in relation to their caring role in general allowed for subjective appraisals of traumatic determinants (e.g., aggression, police involvement, suicide attempts). A similar approach has been used in other studies, including studies with carers of people with psychosis. For instance, Boye and Malt (2002) asked carers to rate the IES in response to the "disorder and hospitalisation". However, this method is potentially problematic because it may have made it more likely that symptoms reported by carers were not tied to one specific

stressor. When symptoms are not tied to a specific stressor, it is difficult to establish for certain that the respondent met Criterion A for PTSD (see introduction; Norris & Hamblen, 2004). However, this is a common criticism of self-report measures of PTSD, many of which are not anchored to a specific traumatic event. Furthermore, epidemiological research has shown that it is not uncommon for people to experience multiple events and respondents may not be aware of the reason why they feel a certain way (Norris & Hamblen, 2004).

This highlights another issue; the current study aimed to assess posttraumatic stress symptoms specifically related to the caring role, however for some participants, especially those with multiple traumatic events, it may have been difficult to determine if some symptoms, particularly arousal symptoms, were specifically associated with traumatic events related to the caring role. A final issue to consider is that some symptoms endorsed on this measure may have been indicative of other co-morbid emotional disorders such as depression and anxiety which overlap with PTSD (Bleich et al., 1997). As outlined by Jackson et al. (2004) most of the criticisms discussed here (e.g., self-report data, symptom overlap, and multiple sources of trauma) are inherent in the majority of posttraumatic stress research, and while they do not invalidate the findings, care needs to be taken when interpreting the results of individual studies.

Some final limitations with respect to the measures used in this study require mention. This study did not provide a measure of inter-rater reliability for the SCID PTSD module. Future research using the SCID with this population should establish and report inter-rater reliability for this assessment. Furthermore, the intrusion interview is not a standardised instrument; therefore it was not possible to compare these findings to other

studies into intrusive imagery. Finally, limitations for the social support and expressed emotion measures have already been discussed.

4.5 Clinical Implications

This study indicates that carers of people with psychosis do report posttraumatic stress symptoms which are associated with significant levels of distress, depression, negative appraisals about caregiving (burden), less adaptive (avoidant) coping and poor physical health. These findings highlight a number of potential clinical and service implications for work with carers and service users with psychosis. We already know that carers play a key role in service user care and outcomes. It is possible that posttraumatic stress symptoms may inhibit the ability of caregivers to help or continue in their support the person with psychosis, which may negatively affect outcomes. For example, carers with posttraumatic stress may have excessively negative perceptions of future possible harm that may lead them to adopt overly cautious safety behaviours, such as avoiding going out of the home or spending all of their available time closely supervising or monitoring their relative to ensure their safety, which may hinder efforts to integrate service users back into the community. Equally, the elevated levels of distress and affective disturbance experienced by carers may leave them no longer in the position to continue their role.

4.5.1 Public health and service level interventions

The findings reinforce the importance of health professionals and policymakers considering the wider impact of psychosis on caregivers. This is especially important given the crucial role many caregivers play in the ongoing care of people with psychosis. One area that may be a particular target for public health policies is the stigma associated with psychosis. This study found a strong correlation between

posttraumatic stress symptoms and negative appraisals of stigma in carers. It is possible that stigma surrounding mental illness in the general population impacts upon carers and may be internalised and may contribute to posttraumatic stress symptoms. Although the cross-sectional nature of the current study prohibits conclusions of causality, previous research with war veterans (Aukst-Margetic, Toic, Furjan, Boban, & Margetic, 2009) and HIV infected individuals (Katz & Nevid, 2005; Adewya et al., 2009) support the possibility that stigma may contribute to the onset and maintenance of posttraumatic stress symptoms. It is well documented that carers of people with psychosis experience stigma (Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007; Kadri, Manoudi, Berrada, & Moussaoui, 2004) and stigma in this group has been associated with poor psychological well-being, such as depression (Magna, Gracia, Hernandez, & Cortez, 2007). There are already campaigns aimed to challenge the stigma associated with mental illness, including, 'Time to Change' run by the leading mental health charities Mind and Rethink Mental Illness, launched in 2007. This campaign reports some initial success in reducing discrimination levels and some improvement in public attitudes (Time to Change, 2009). The current findings may support and inform current and future initiatives aimed to combat the stigma associated with mental illness particularly psychosis.

The strong relationship between posttraumatic stress symptoms and reports of problems with services, in carers of people with psychosis, suggests that better engagement and support of carers by mental health services may impact on the experience of posttraumatic stress symptoms in this group. Although families report they need information and support from mental health services (Reid, Lloyd, & Groot, 2005), studies have found that only a minority of carers receive support or information from mental health services (Dixon et al., 1999); more than half have no contact with services

(Young, Sullivan, Burman, & Brook, 1998). The employment of carer support workers in some community mental health teams does seek to address some of these issues; however, these roles are not yet widely available.

4.5.2 Family Intervention

Family intervention is an evidence-based recommended therapy for service users with their carers that has been found to significantly reduce rates of relapse and readmission in people with psychosis (Bird et al., 2010; NICE, 2009; Pharoah et al., 2010). Information sharing and problem solving, form two of the core components of the intervention. It is possible that posttraumatic stress symptoms may interfere with the ability of carers to participate in family intervention. For example, therapy activities such as psychoeducation may negatively interact with aspects of their own symptomatology such as re-experiencing or avoidance. The strong relationship between appraisals of stigma and posttraumatic stress symptoms, also suggests that it is possible some carers may not want to engage with mental health services, including the evidence-based therapies on offer such as family intervention, due to the illness related stigma. It was qualitatively noted by the researcher that one carer reported she had specifically kept the research meeting a secret from a close friend because she did not want them to discover her son had psychosis.

A need for family intervention is also suggested by the strong relationship between negative appraisals regarding the effects on family and posttraumatic stress symptoms, in addition to the finding that several negative intrusive images reported by carers in this study featured the relationship between children in the family and the service user. It is likely that family intervention could also serve as a useful mechanism for carers with posttraumatic stress symptoms to address some of their concerns about their caring

role, help them to relate to the service user as they are now and not as they were before, and to construct relapse plans that afford them some control about future events.

4.5.3 Screening measure

Early detection of posttraumatic stress symptoms is also thought to be important in preventing the development of chronic posttraumatic stress symptoms (Ehlers & Clark, 2003). Screening for posttraumatic stress symptoms in carers may be facilitated by a brief screening measure such as The PTSD Checklist-Civilian Version (PCL-C; Weathers, Litz, Huska, & Keane, 1994). A screening tool that could detect those at highest risk of developing posttraumatic stress symptoms could also be developed and routinely administered to carers of people with psychosis at the time of first episode and then evaluated for its effectiveness in identifying carers at risk of developing chronic symptoms of posttraumatic stress disorder. An assessment at this stage would establish the need for psychological support or at least provide an opportunity to provide carers with information about how to contact services at a later date should they feel it necessary. If posttraumatic stress symptoms were identified in carers of people with psychosis this may indicate the need for individual interventions as well as family interventions.

4.5.4 Individual interventions for posttraumatic stress symptoms in carers of people with psychosis

Reducing posttraumatic stress symptoms in carers may improve outcomes for carers, which in turn may impact on service user outcomes. Unfortunately, levels of support for carers is generally low (Kuipers, 2010) and their contact with clinical teams is generally via the telephone and often only during times of crisis (Dixon, Lucksted, Stewart, & Delahanty, 2000). Nevertheless, the current study illustrates the importance of negative

cognitive appraisals and avoidant coping strategies as correlates of posttraumatic stress symptoms in carers of people with psychosis and as areas for intervention. Current guidelines for the treatment of PTSD (NICE, 2005; Nemeroff et al., 2006) recommend a period of watchful waiting followed by trauma-related cognitive-behavioural therapy, which, for example, may focus on negative appraisals about events related to caregiving and its sequelae. Barton and Jackson (2008) also report that a writing intervention was associated with a significant reduction in avoidance symptoms in a sample of carers of people with psychosis. Specifically, carers who wrote about their caregiving experience were less likely to avoid reminders and feelings associated with the service user's first episode of illness. Within individual interventions, some carers may also benefit from a specific focus on stigma associated with psychosis. The strong association between posttraumatic stress and negative appraisals of stigma in the current sample of carers indicates that stigma should be combated at an individual level in addition to the public health level anti-stigma campaigns.

There are a number of interventions designed to treat distressing intrusive imagery specifically, including imagery rescripting. Imagery rescripting describes a collection of imagery techniques that aim to change the negative meanings associated with autobiographical memories of traumatic /distressing experiences (Stopa, 2011). Research has shown that intrusive images can be rescripted in therapy to bring about rapid symptom reduction (e.g., Brewin et al., 2009; Wheatley et al., 2007). Imagery rescripting has recently been successfully used to counter troublesome mental imagery in the context of PTSD, depression, and social phobia (Arntz & Weertman, 1999; Wild, Hackman, & Clark, 2008; Hackmann et al., 2004; Smucker, Dancu, Foa, & Niederee, 1995; Wheatley et al., 2007; Brewin et al., 2009). There were, at the time of writing, no known studies using imagery techniques with carers. However, given imagery

rescripting has been successfully used to counter troublesome mental imagery and negative intrusive imagery has been found in carers of people with psychosis, it seems promising that this intervention could have some benefits with carers.

4.6 Suggestions for Further Research

One important area for future research would be to measure other variables that are seen to play a key role in the onset and maintenance of posttraumatic stress symptoms as outlined in the cognitive model of PTSD (Ehlers & Clark, 2000) and the stress, appraisal, and coping framework (SAC; Lazarus & Folkman, 1984). For example, while avoidant coping was measured and found to be associated with posttraumatic stress symptoms, there are a number of other maladaptive cognitive and behavioural strategies outlined in the Ehlers and Clark (2000) model, such as rumination (e.g., thinking about how the illness could have been avoided or prevention) which would also be important to explore, as these are hypothesised to increase and maintain posttraumatic stress symptoms. In line with testing this model and as already mentioned, it would be important for future research to use a more detailed measure of social support. In addition, because of the cross-sectional study design, the causal direction of relations between posttraumatic stress symptoms and stress/coping predictors is unclear. Future research with larger samples that use statistical model testing approaches able to investigate the meditating and moderating effects of predictors are required to further explore the application of these theoretical models to the understanding posttraumatic stress symptoms in carers of people with psychosis. While negative appraisals of the trauma and its sequelae were found to be strongly related to posttraumatic stress symptoms, a true test of the model as applied to this population would be to see if modifications of appraisals results in reductions of posttraumatic stress symptoms in carers of people with psychosis. Finally, an exploration of risk factors or predictors for

developing posttraumatic stress symptoms, for example, pre-existing mental health conditions amongst caregivers, would also be important.

Given the number of measures included in the current study and the desire to minimise the assessment burden on participants, the SCID PTSD module was discontinued if the screening item was not endorsed and following this, discontinued if the participant did not meet the threshold for a particular criterion. In contrast, some other studies (e.g., Manne et al., 2004; Alderfer et al., 2005) have asked all items on this measure even when participants did not endorse items for a particular criterion, thus allowing for a more detailed analyses of symptoms cluster (based on criterion) and for the identification of "subthreshold" PTSD. As mentioned previously, subthreshold PTSD is seen to be an important phenomenon to assess as it has been associated with social and occupational impairment comparable to full PTSD (Stein et al., 1997). Future research may like to adopt this approach when using the SCID PTSD module with carers of people with psychosis.

In carers of people with psychosis, Martens and Addington (2001) found a relationship between poor psychological well-being and short duration of illness. This suggests that it may be useful to study patterns of posttraumatic stress symptoms over time among carers in an effort to identify time points when intervention could be most effective.

Another area of future research that may build upon the current study is to explore the role of resilience factors (McFarlane & Yehuda, 1996) or posttraumatic growth (Cadell, 2003). Given the number of stressful life events associated with caring for someone with psychosis, it is striking that some carers were better able to cope than others and did not report high levels of posttraumatic stress symptoms. Szmukler et al. (1996)

argue that it is important to remember that many carers of people with psychosis cope effectively with demanding, enduring problems and that identifying and understanding good coping is as important as detecting psychopathology. They suggest that personal characteristics such as resilience and optimism may contribute to good coping. Similarly, Kuipers et al. (2010) describe positive caregiving relationships characterised by positive appraisals and effective coping strategies, and argue that improving carer outcomes requires a theoretical and practical understanding of the mechanisms that optimise the positive aspects of the role, in addition to those that develop and maintain distress. It would be informative to examine positive aspects of successful coping and positive cognitive appraisals, in relation to posttraumatic stress symptoms, in this population. Interestingly, the current study found a moderate negative correlation ($p < .05$) between positive appraisals of caregiving, specifically good aspects of the relationship, and hyperarousal symptoms. Although a causal relationship cannot be assumed, it is possible that positive appraisals of caregiving may serve as a protective factor against the development of posttraumatic stress symptoms. Carers may have appraised their trauma as an opportunity for personal growth and to develop greater awareness of their inner skills (e.g., Chen & Greenberg, 2004). Carers reporting positive relationships with service users may feel better equipped and motivated to respond to the negative sequelae of their trauma. We know from the literature that caregivers can report positive caregiving experiences including reports of resilience and growth (Veltman et al., 2002). However, further research is required to identify the factors contributing to resilience in carers of people with psychosis and to develop effective interventions and service approaches that target and promote resilience in this population.

4.7 Conclusions

The findings from this study lend empirical support to the importance of applying stress and coping models to understand posttraumatic stress symptoms in carers of people with psychosis. The identification of posttraumatic stress symptoms reveal the complexity of carer adjustment to stressors related to the caring role. This study used a cross-sectional design to explore the relationship between posttraumatic stress symptoms and a broad range of carer characteristics. As predicted, greater levels of posttraumatic stress symptoms were associated with: negative appraisals of caregiving, negative appraisals of trauma, greater levels of avoidant coping, and lower reported physical health. The current study did not find support for relationships between posttraumatic stress symptoms and social support, expression emotion, and sleep quality. However previous support for these relationships in the literature and limitations of the current study, suggests these areas are worth further investigation, especially given the relationship between expressed emotion and relapse in service users and the potential protective role of social support. An extension of this study would be to measure other variables believed to play a role in the onset and maintenance of posttraumatic stress symptoms, including resiliency factors, and to use statistical model testing approaches that investigate the meditating and moderating effects of predictor variables implicated in the theoretical models (i.e., SAC and the cognitive model of PTSD). Furthermore, it would be valuable to study patterns of posttraumatic stress over time among carers, to identify time points when interventions would be most effective. Overall, the findings contribute to a better understanding of posttraumatic stress symptoms in carers of people in psychosis and can be used to shape interventions designed to meet the needs and improve outcomes for both carers and service users.

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6 Appendices

Appendix 1: Professional Information Sheet

Understanding Carer Experiences in Psychosis

Institute of Psychiatry
at The Maudsley

Department of Psychology
Third Floor PO78
Institute of Psychiatry
London SE5 8AF
Tel. 07748922799
Email: cara.kingston@kcl.ac.uk

KING'S College LONDON
Founded 1829

PROFESSIONAL INFORMATION SHEET

RESEARCH PROJECT
Understanding Carer Experiences in Psychosis

THE STUDY
Carers can play a significant role in facilitating the recovery of service users with psychosis. However, we know far less about carers' experience of stress and stressful life events and their relationship with wellbeing and caregiving role. This study seeks to improve our understanding of these areas and offer a brief targeted intervention for three carers presenting with stressful reactions.

INCLUSION CRITERIA

We are currently looking for carers who meet the following criteria:

- ***Parents, relatives, spouses, partners & friends of the identified service user, who are in a caregiving role and have regular weekly contact with the patient for at least ten hours. This may include phone contact.***
- **aged 18 or over**
- **have sufficient English to complete the assessment**

What does it involve for participants?
The study is divided into two parts.

- Part 1 involves a single meeting with a researcher where participants will be asked to complete some questionnaires and an interview. This will take approximately 75 minutes to complete.
- Part 2 will offer three participants from Part 1 a brief three session intervention designed to reduce their stressful reactions. Each session with the researcher will last around 60-90 minutes.

Will participants be reimbursed for their expenses?
Part 1 Participants will be offered £15 to cover reimbursements
Part 2 Participants will be offered £45 cover reimbursements over the three sessions

What does it involve for staff?
If you know of any carers of service users who are interested in participating in this study or would like further information about the study; please contact Cara Kingston on (07748922799) or email (cara.kingston2@slam.nhs.uk).

ETHICAL APPROVAL
This study has been approved by the South London and Maudsley NHS Foundation Trust and the National Research Ethics Service Committee London – Stanmore (Ref: 11/LO/0498).

RESEARCH TEAM
Cara Kingston – Researcher and Trainee Clinical Psychologist
Professor Elizabeth Kuipers – Professor of Clinical Psychology
Dr Juliana Onwumere – Research Clinical Psychologist
Dr Nadine Keen – Chartered Clinical Psychologist

Thank you very much for taking time to read this information sheet
If you have any questions about the study please contact Cara Kingston by email at cara.kingston2@slam.nhs.uk or phone her on **07748922799.**

Appendix 2: Cover Letter

Institute of Psychiatry

at The Maudsley

Understanding Carer Experiences in Psychosis

KING'S College LONDON Founded 1829

Cara Kingston
Department of Psychology
Third Floor ASB PO78
Institute of Psychiatry
London SE5 8AF

Tel. 02078480224
Email: cara.kingston@kcl.ac.uk

Dear

Re: Understanding Carer Experiences in Psychosis

I am currently undertaking some research to improve our understanding of the experiences of people (sometimes described as carers) who provide support and care for someone with psychosis. I am undertaking this research within adult mental teams in the [Insert NHS Trust/Support Group]. I am writing to you because you have been identified as someone in close and regular contact with a service user.

I have included some information for you about the study and would be really grateful if you would take some time to read it and consider whether you would be interested in participating.

Thank you very much for taking the time to consider taking part in this study. If you have any further questions about the study or if there is anything you would like to discuss, please don't hesitate to contact me either by phone or email.

I will contact you again in about a week's time to see if you have any further questions and to ask whether or not you would like to take part.

I would like to take the opportunity to thank you for reading this letter.

I look forward to speaking with you soon.

Best wishes,

Cara Kingston
Trainee Clinical Psychologist

Appendix 3: Participant Information Sheet

Understanding Carer Experiences in Psychosis

Institute of Psychiatry

at The Maudsley

Cara Kingston
Department of Psychology
Third Floor ASB PO78
Institute of Psychiatry
London SE5 8AF
Tel. 07748922799
Email: cara.kingston@kcl.ac.uk

KING'S College LONDON Founded 1829

PARTICIPANT INFORMATION SHEET- PART 1

Understanding Carer Experiences in Psychosis:
A cross sectional study and case series – PART 1

Please take time to read the following information carefully.

What am I being asked to do?
You are being invited to take part in a research study. Before, you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. We encourage you to talk to others about the study, if you wish.

Part A: tells you the purpose of this study and what will happen to you if you take part.

Part B: gives you more detailed information about the conduct of the study. If there is anything that is unclear or you would like further clarification, please feel free to contact the researcher (contact details below). Take time to decide whether or not you wish to take part.

Thank you for taking time to read this. Please feel free to ask the researcher any questions about the study and what it involves.

PART A

What is the purpose of the study?
The study aims to improve our understanding of the experience of stress in carers of people with psychosis. It will look at carers' experience of stressful life events and links with their emotional and physical well-being, styles of coping and their caregiving experience.

Why have I been asked to take part?
We are inviting 44 carers of service users with psychosis using adult services in the South London and Maudsley NHS Foundation Trust.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do take part, you will be given this information sheet to keep and will be asked to sign a consent form. Please note that you are still free to withdraw from the study at any time and without giving a reason. Your decision to withdraw at any time, or a decision not to take part, will not affect the service or standard of care you or the service-user receive from their clinical team.

Can I change my mind once I am in the study?
Yes. You can withdraw from the study at any time without giving a reason.

3. Who is carrying out the study?

The study is being carried out by Cara Kingston, Dr Juliana Onwumere, Prof Elizabeth Kuipers and Dr Nadine Keen from the Department of Psychology at the Institute of Psychiatry, King's College London.

4. What will happen to me if I take part?

If you agree to take part, we will ask you to sign a consent form. Participation involves one meeting with the researcher. The researcher will arrange a time to meet with you at either the service users' team base, Institute of Psychiatry, your home or wherever proves to be most convenient for you. You will be asked to complete a small handful of questionnaires which elicit your views on your emotional and physical health, caregiving experiences and stressful life events. You will also be asked to complete a brief interview on the thoughts and images associated with life events and your thoughts about the service user. The interview will be audio recorded. There are no right or wrong answers to the questions or the interview.

How long will the study take?

The completion of the questionnaires and the interview will take around 75 minutes in total. You can take breaks if you wish.

Will I be reimbursed for any expense?

Yes, you will receive £15 at the end of the meeting to cover your travel, refreshments and other expenses.

5. When and where will the study take place?

As before, if you decide to take part, Cara Kingston will arrange to meet with you at a time that is convenient, either at the service user's local Community Mental Health Team or in an interview room at the Institute of Psychiatry. Cara may also be able to meet with you at home if this is more convenient for you.

Will the information I provide be confidential?

All your responses to the questionnaires and the interview are confidential and will be kept anonymously (i.e. will only be identifiable by a number, not your name). With your consent, we will inform your service user's clinical team that you are taking part in the study. The information you give will be treated as strictly confidential. It will usually be available only to the research team. However, the researcher will share with the clinical team any important information that is relevant to the care you and/or the service user receive. To ensure confidentiality, the service user will not be informed of your responses.

Further, if you tell us something that gives us cause to believe that you may pose a risk of serious harm to yourself or others, or make a criminal disclosure which requires action, including passing information to others, the research team will take this action as appropriate. Where possible, we would aim, to discuss this process with you.

How will you keep the information I provide?

All information, including audio recordings, will be kept anonymously in a locked cabinet and/or password protected computer file. Only members from the research team will have access to the information. All information will be securely destroyed in accordance with King's College London guidelines, which currently recommends research data be kept for a period of 7 years. Detailed information about what will happen to the results is given in Part B.

6. What are the possible disadvantages and risks of taking part in this study?
It is not expected that participation in the study has any risks. Some people may find the questionnaires lengthy and the questions personal in nature. Some people may find it upsetting to talk about their thoughts, feelings, and experiences. If you find any of the questions upsetting and would like to talk about this please let the researcher know or talk to your family doctor. You will have the opportunity to take breaks and engage in some relaxation exercises if you should wish to do so.

7. What are the possible benefits of taking part?
We do not expect the study to directly help with your carer role although some people report finding the chance to answer questions and talk about their experiences useful and interesting. We do hope that the information collected will help us to understand better the experience of distress in people who care for people with psychosis. This may help to guide future interventions for carers and service users.

What should I do if I have any problems?
Any complaint of the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information on this is given in Part B.

8. Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been approved by the National Research Ethics Service Committee London – Stanmore (Ref: 11/LO/0498).

This completes Part A of the Information Sheet
If the information In Part A has interested you and you are considering participation, please continue to read the additional information in Part B before making a decision.

PART B

Complaints

If you have any concerns about any aspect of this study, please speak to the researcher who will try to address your questions (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital or clinical team. You can also contact the South London and Maudsley NHS Patient Advisory Liaison Service (0800 731 2864; pals@slam.nhs.uk) or the Trust's Research and Development office (0207 848 0790).

Although we do no expect the study to have any risks, in the event that you are harmed due to the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against King's College London but you may have pay for legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

What will happen to the results of the study?

A summary of the results will be submitted to a scientific journal for publication and written up as a doctoral thesis by Cara Kingston. It may also be presented at a conference. You will not be personally identified in any report/publication. If you are interested in receiving a written summary of the findings of the study, please tick the box on the consent form. We also plan to publish a summary of our findings on the website: mentalhealthcare.org.uk.

Contact details for further information

If you have any questions about the study or are unsure whether you qualify to take part, you are welcome to discuss your participation, in confidence, with Cara Kingston (**cara.kingston@kcl.ac.uk, Tel:** 07748922799).

Appendix 4: Consent Form

Understanding Carer Experiences in Psychosis

Institute of Psychiatry

at The Maudsley

Cara Kingston
Department of Psychology
Third Floor ASB PO78
Institute of Psychiatry
London SE5 8AF
Tel. 02078480224
Email: cara.kingston@kcl.ac.uk

KING'S College LONDON Founded 1829

CONSENT FORM – PART 1

Title of Project: **Understanding Carer Experiences in Psychosis: A cross sectional study and case series – PART 1**

Name of Researcher: **Cara Kingston**

1. I confirm that I have read and understand the Information Sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the interview will be recorded and that audio recordings will be kept anonymously in a locked cabinet. ☐
4. I give permission to the researcher to inform the service user's clinical team of my participation in the study and to share any clinically important information that I discuss during the research with the clinical team. ☐
5. I understand that the researcher may wish to use direct quotes from descriptions of experiences in reports on this research; the researcher will remove all personal details or information that could identify me in any way first. I give permission for the researcher to use quotations in this way. ☐
6. I am interested in receiving a written summary of the main results of the study once the research is completed. ☐
7. I agree to participate in the above study. ☐
8. I consent to be contacted regarding future studies. I understand that this does not oblige me in any way to take part in these studies ☐

Name of Participant	Date	Signature

I have explained the purpose of the study to the participant and have answered their questions honestly and fully.

Name of Person Taking Consent	Date	Signature

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Appendix 5: Demographics Form

GENERAL INFORMATION QUESTIONNAIRE

Participant number:
Date of assessment:

For each question, either write the answer on the line or tick the box which most applies to you. Some questions may have more than one answer.

1. Date of birth ----------/----------/---------
(dd/mm/yyyy)

2. Gender
□ male
□ female

3. Ethnic background
□ White □ Black Caribbean
□ Black African □ Black Other
□ Indian □ Pakistani
□ Other- please specify

4. Is English you first language?

□ Yes
□ No Which is your first language? _____

5. What is your relationship status?

□ Single □ Married
□ Divorced □ Separated
□ Widowed □ Cohabiting living with another
□ Other – please specify: _____

6. Are you
□ employed full-time □ a full-time student
□ employed part-time □ a part-time student
□ self-employed □ unemployed
□ a homemaker □ retired
□ other – please specify: _____

7. How old is the person you care for? _____

(Please turn over the page to continue…)

8. How would you specify the relationship to the person you care for? Are they your:

□ Daughter	□ Son
□ Brother	□ Sister
□ Partner	□ Mother
□ Father	□ Friend

□ Other – please specify: _____

……

9. Does the person live with you?

□ Yes
□ No

……

10. How long have you been in this caring role? _____

……

Appendix 6: Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997)

Removed due to copyright restrictions

Appendix 7: Adapted Structured Clinical Interview for DSM Disorders (SCID-I), PTSD Module (First et al, 2002)

Removed due to copyright restrictions

Traumatic events specifically related to caring for a person with psychosis
(To be inserted into SCID)

Sometimes carers of people with psychosis live through or witness stressful life events related to their caring role.

At any time, during your caring role, have any of these kinds of things happened to you?

- ❑ Physical violence by service user
- ❑ Verbal abuse and/or threats by service user
- ❑ Involuntary hospital admission of service user
- ❑ Suicide attempt or self-harm by service user
- ❑ Experience of psychiatric hospital environment due to admission of service user
- ❑ Informed of mental health diagnosis of service user
- ❑ Discrimination and/or stigma (for example: negative attitudes or prejudice; harassment; deliberate avoidance of you or the service user by others; denied access to work and/or community facilities)
- ❑ Severe financial burden/bankruptcy
- ❑ Other risky/unpredictable behaviour by service user (for example: substance misuse; damage to property). Please specify:

_____

_____

- ❑ Other traumatic event. Please specify:

_____

_____

Appendix 8: Experience of Caregiving Inventory (ECI; Szmukler et al., 1996)

Removed due to copyright restrictions

Appendix 9: Posttraumatic Cognitions Inventory (PTCI; Foa et al., 1999)

Removed due to copyright restrictions

Appendix 10: Abbreviated Coping Orientations to Problems Experienced (COPE) Inventory (Carver, Scheier, & Weintraub, 1989; Carver & Scheier, 1994)

Removed due to copyright restrictions

Appendix 11: Confidante Question

CONFIDANT QUESTION

Do you have someone in whom you can confide?

Please mark as appropriate: *Yes / No*

Appendix 12: The General Health Questionnaire-28 (GHQ-28; Goldberg & Hillier, 1979)

Removed due to copyright restrictions

Appendix 13: Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

Removed due to copyright restrictions

Appendix 14: The Five Minute Speech Sample (FMSS; Magana et al., 1986)

Removed due to copyright restrictions

Appendix 15: RAND 36-item Health Survey Questionnaire (RAND-36; Hays et al., 1993)

Removed due to copyright restrictions

Appendix 16: Pittsburgh Sleep Quality Index (PSQI; Buysse et al., 1989)

Removed due to copyright restrictions

Appendix 17: Intrusion Interview (Hackman et al., 2000; Hackman et al., 2004; Patel et al., 2007)

Participant Number: **Date of Interview:**

Semi Structured Interview Script: Intrusive Images
Based on interviews developed by Patel et al. (2007), Hackman et al. (2004) and Hackman et al. (2000)

PART 1: Introduction to Identifying Images

Begin by normalising the experience of intrusive images:

For the next part of the study, I will be asking you about "Images in the mind's eye" or mental images. First, I want to explain what we mean by Mental Images. When we think, we can do this in different ways. Often we think in words, but at other times we can think in images or pictures, like photos or a video clip. Can you for example try to think of a lemon? Can you think about in the form of a picture that you can see in your mind's eye? You may find it easier to briefly close your eyes to do this if that feels comfortable.

So mental images are visual pictures can be like seeing a brief snapshot or watching a movie clip in your mind's eye.

It is extremely common for people to experience intrusive images. Sometimes they are pleasant, for example seeing images of a happy time or occasion e.g. a wedding. When we recall that image there may be sounds, smells, feelings or thoughts associated with that image.

Can you think of a time when you were happy or doing something you enjoyed? Spend some time thinking about this time…do you have an image or picture of it in your mind? What is happening in the image? Can you describe what you see, hear, smell, taste, feel in the image?

PART 2: Exploring Negative Intrusive Memories and Images

People also often experience similar reactions when thinking about negative or unhappy events. This can feel like a picture, photograph or film that comes into our heads when we don't want it to. The images may be incomplete or fleeting. Sometimes these images can be overwhelming to think about and the images may be very vivid. You may also notice sounds, smells, memories, thoughts or emotions associated with the images.

I would now like to spend some time talking and thinking with you about times when you may experience images that feel negative and intrusive.

1. Have you ever had memories, images, smells or sounds that come into your mind when you are stressed, anxious or depressed?

2. Have you ever had either an intrusive image, perhaps associated with a past traumatic or upsetting event?

3. Have you ever had intrusive images, smells or sounds, however fleeting, associated with your caring role?

4. Have you had any images of particularly feared outcomes associated with your caring role?

5. In the last week have you had any particular mental pictures or images that keep coming (spontaneously) to your mind however fleeting? **(If last week was exceptional then ask about a typical week).** (Prompts – When you were feeling the most anxious, stressed or low in mood OR memories of particular negative events OR intrusive images of a particularly feared outcomes)

YES / NO

6. What is the most distressing image? **(If more than one then inform the carer that we will just be concentrating on the most distressing image).**

Participant Number: **Date of Interview:**

If the client reports experiencing any recurrent image that comes into their mind: ask them to close their eyes and concentrate on the image. Then the following questions are asked:

7. Answering yes (2), no (0) or maybe (1) do you have a clear image in your mind?

Content

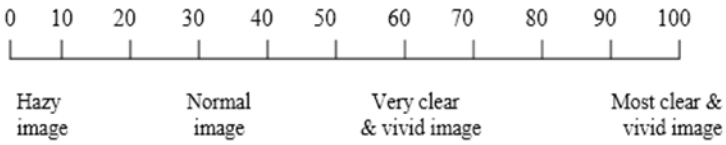
8. What can you see? (0 = nothing, 1 = something)

9. What can you hear? (0= nothing, 1 = something)

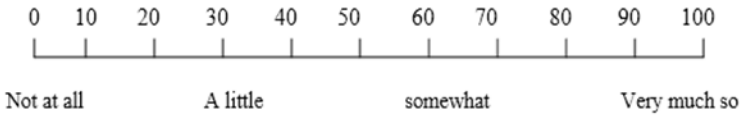
10. What can you smell (0 = nothing, 1 = something)

11. Can you taste or feel anything in your body (0 = nothing, 1 = something)

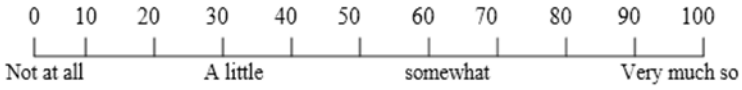
12. Please rate the **vividness** of your image:



13. Do you experience **physical sensations** when you have this image?



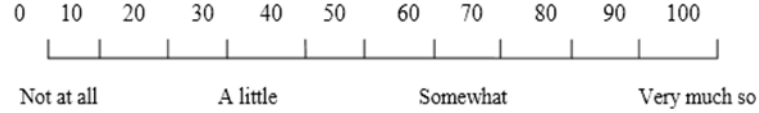
14. What are the **emotions** that you associate with this image? How strongly do you feel that emotion?



Sad: Guilty: Ashamed: Other *(specify):*

Angry: Anxious: Helpless:

15. When you have this image, how **real** does this image feel? *(Prompt - At the time that you have the image, do you feel as if it is really happening?)*



Participant Number: **Date of Interview:**

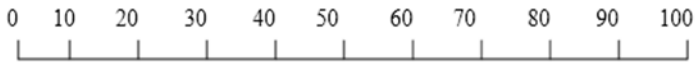
16. How **many times** did you experience the intrusive image in the last week?

once or twice a week / several times a week / every day / many times a day

17. When you experience the intrusive image on average **how long** does it last?

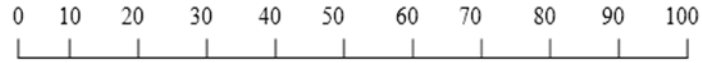
Seconds / minutes / hours

18. How much did the intrusive image **interfere** with your daily life?



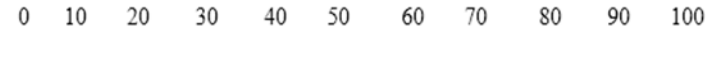
Not at all Moderately Severely

19. How **controllable** was your intrusive image in the last week?



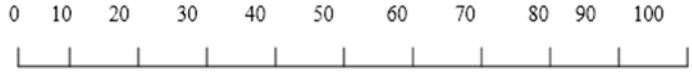
Not at all Moderately Completely

20. How **distressing** was this image for you?



Not at all Moderately Severely

21. How **threatening** was this image for you?



Not at all extremely

Meaning

22. What does this image mean for you? (0 = not able to elicit meaning; 1 = able to elicit something)

23. What does the image tell you about yourself? (0 = nothing; 1 = something)

24. What does the image tell you about others? (0 = nothing; 1 = something)

25. What does this image tell you about the world? (0 = nothing; 1 = something)

Conviction

How strongly do you believe that this means _____

_____? (0 = not at all to 100 = extremely)

Participant Number: **Date of Interview:**

Associated memories

26. When in your life did you first experience the sort of sensations, emotions and thoughts associated with this image?

27. Do you have any particular memories associated with this image? (0 = no; 1 = yes)

28. Do the feelings you have when you focus on the image remind you of any past memories or events in your life? (0 = no, 1 = yes)

PART 3
If the person does have a clear memory of when they first experienced these thoughts and feelings they will be asked to think about the memory for a few moments and then the following questions are asked.

29. Answering yes (2), no (0) or maybe (1) do you have a clear sense of the memory in your mind?

Content
30. What can you see? (0 = nothing, 1 = something)

31. What can you hear? (0 = nothing, 1 = something)

32. What can you smell (0 = nothing, 1 = something)

33. Can you taste or feel anything in your body? (0=nothing, 1 = something)

Context
34. When did this episode happen? How old were you at the time of this memory?

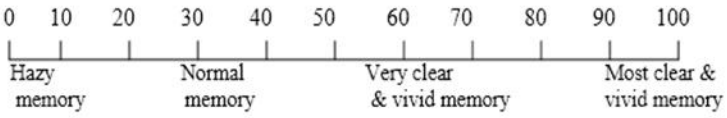
_____ Years

35. What was happening before the memory you have just described to me? (0 = nothing; 1 = something)

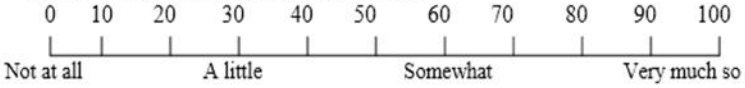
36. Were there any events leading up to this moment? (0 = nothing, 1 = something)

Participant Number: **Date of Interview:**

37. Please rate the **vividness** of your memory for the experience:



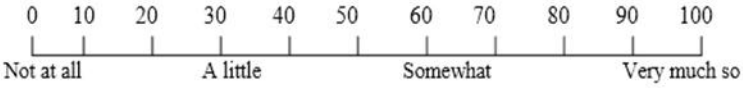
38. How do you feel when you focus on this memory? How strongly do you feel that **emotion** when thinking about the memory?



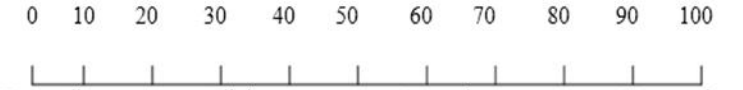
Sad: Guilty: Ashamed: Other *(specify):*

Angry: Anxious: Helpless:

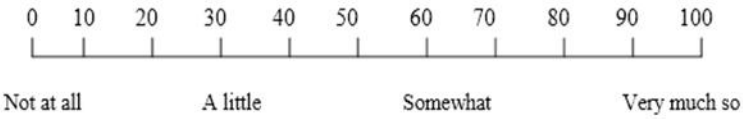
39. When you have this memory, does it feel like it is not just a past event but is **happening all over again**? *(Prompt - At the time that you have the memory, do you feel as if what happened then is happening all over again?)*



40. When you remember the event do you **re-experience emotions** the same as, or very similar to, those that were felt in the actual event?



41. When you remember the event do you **re-experience physical feelings** the same as, or very similar to, those that were felt in the actual event?



42. How **many times** have you thought about this memory in the last week?

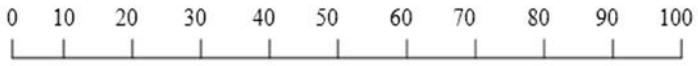
once or twice a week / several times a week / every day / many times a day

43. When you experience the memory on average **how long** does it last?

Seconds / minutes / hours

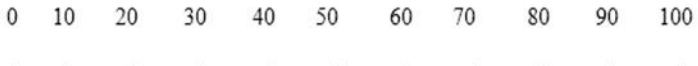
Participant Number: **Date of Interview:**

44. How much did the memory **interfere** with your daily life?



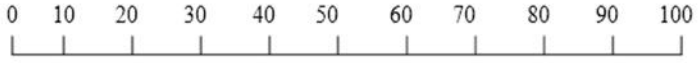
Not at all Moderately Severely

45. How **controllable** was your memory in the last week?



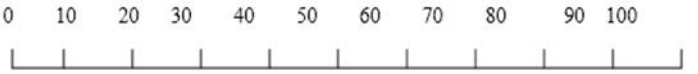
Not at all Moderately Completely

46. How **distressing** is your memory?



Not at all Moderately Severely

47. How **threatening** is this memory for you?



Not at all Extremely

Meaning

48. What does this memory mean for you? (0 = not able to illicit meaning, 1 = able to illicit something)

49. What does the memory tell you about yourself? (0 = nothing, 1 = something)

50. What does the memory tell you about others? (0 = nothing, 1 = something)

51. What does this memory tell you about the world? (0 = nothing, 1 = something)

Conviction

52. How strongly do you believe that this means_____
_____? (0 = not at all to 100 = extremely)

Appendix 18: Scatterplots of correlations between posttraumatic stress symptoms and key variables

Figure 9. Scatterplot of the correlation between posttraumatic stress symptoms and negative caregiving appraisals (N = 32)

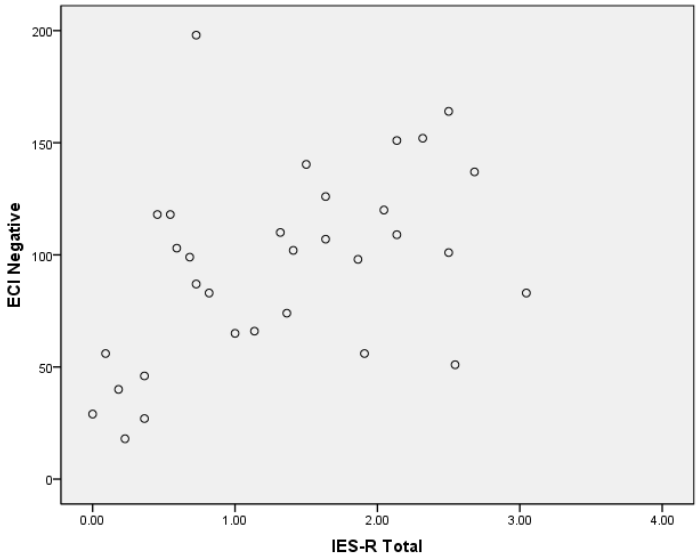


Figure 10. Scatterplot of the correlation between posttraumatic stress symptoms and negative cognitions about the self (N = 32)

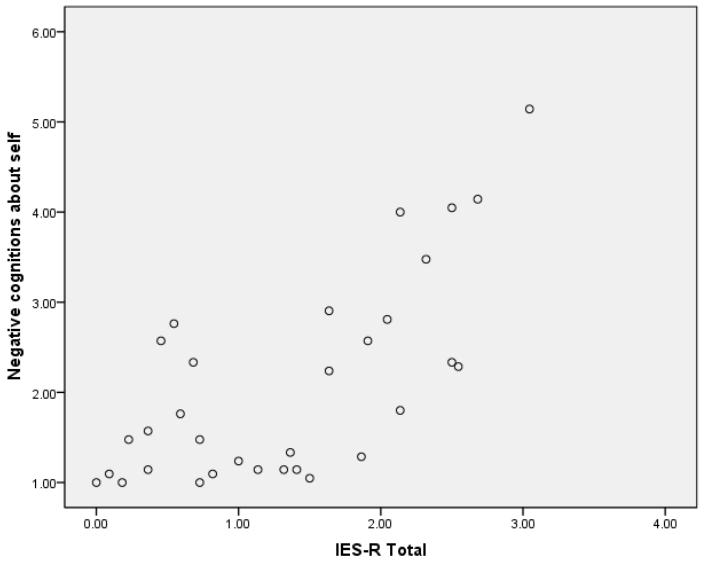


Figure 11. Scatterplot of the correlation between posttraumatic stress symptoms and self-blame for the trauma (N = 32)

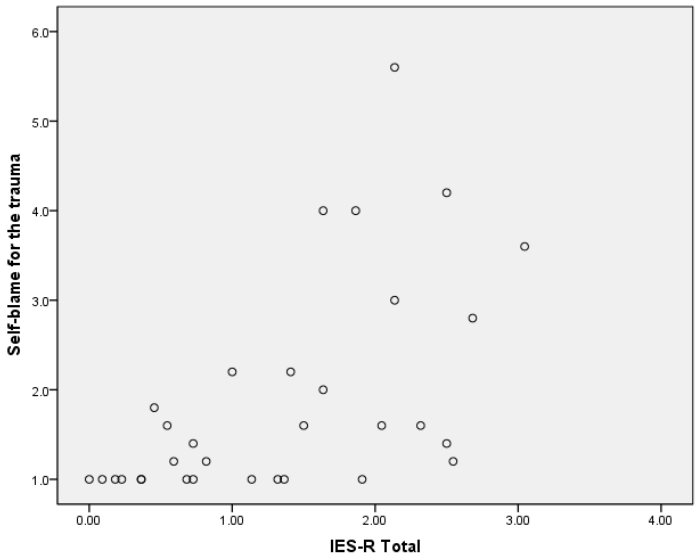


Figure 12. Scatterplot of the correlation between posttraumatic stress symptoms and avoidant coping (N = 32)

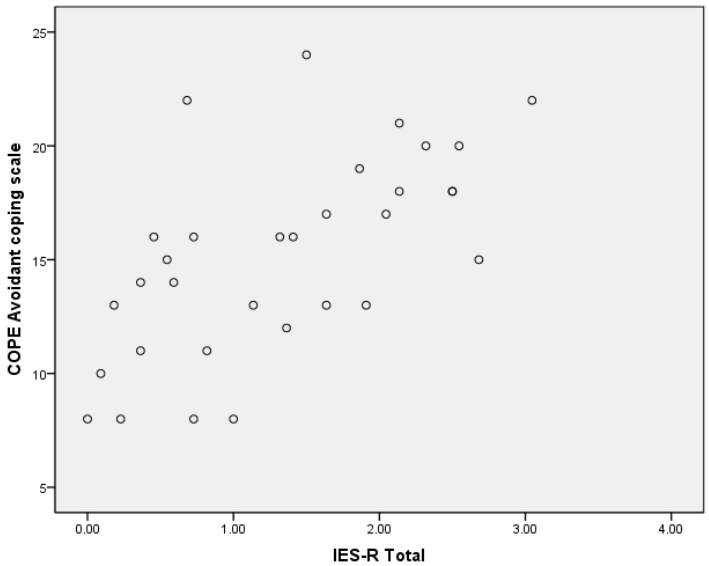


Figure 13. Scatterplot of the correlation between posttraumatic stress symptoms and distress as measured by GHQ-28 (*N* = 32)

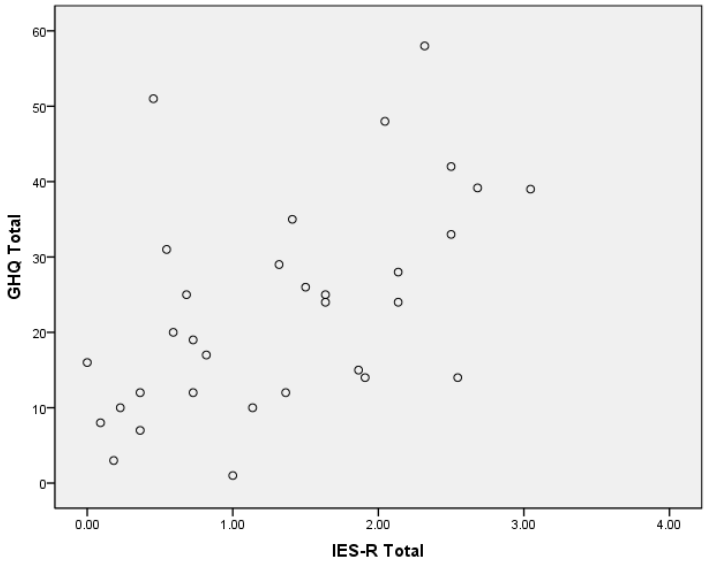


Figure 14. Scatterplot of the correlation between posttraumatic stress symptoms and depression as measured by HADS (*n* = 31)

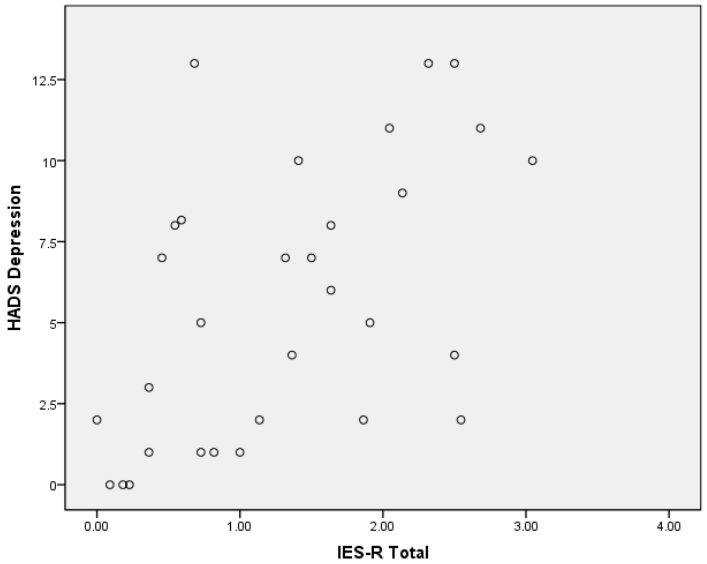


Figure 15. Scatterplot of the correlation between posttraumatic stress symptoms and anxiety as measured by HADS (*n* = 31)

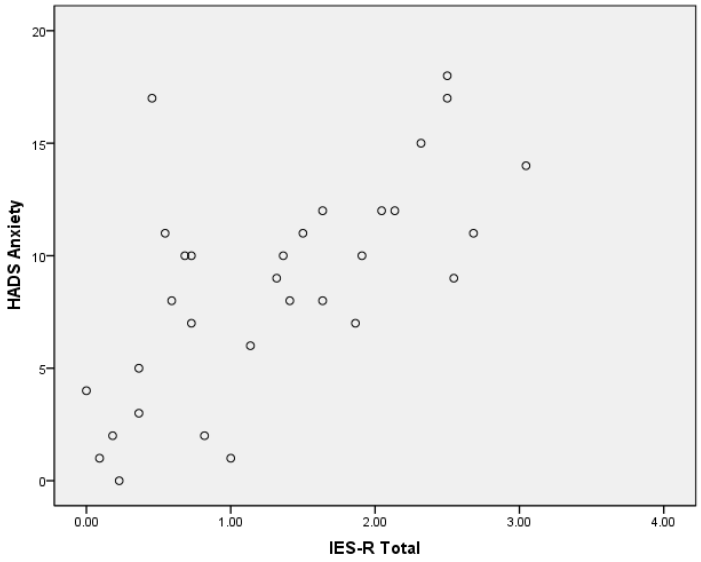
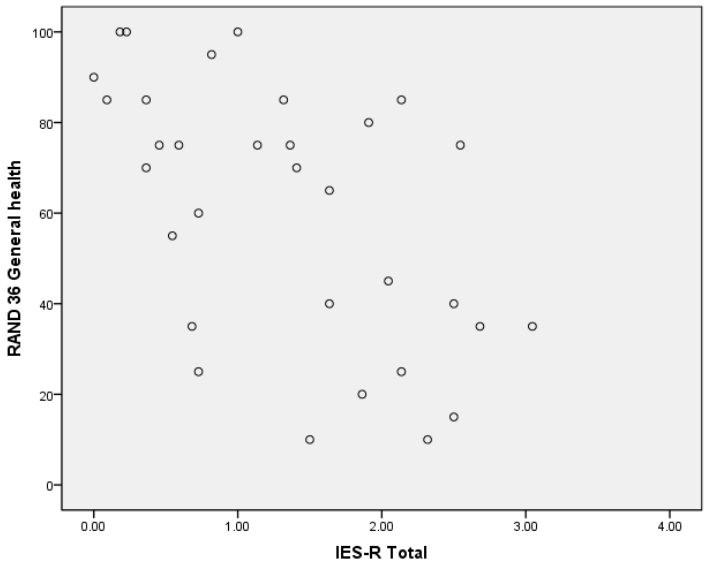


Figure 16. Scatterplot of the correlation between posttraumatic stress symptoms and general health as measured by RAND-36 (*n* = 32)



SERVICE EVALUATION

Parents' experiences of a specialist mental health intervention service for children with Autistic Spectrum Disorder

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Cara Kingston

Institute of Psychiatry, King's College London

Supervised by Dr. Ann Ozsivadjian

Guy's and St Thomas' NHS Foundation Trust

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Abstract

Background: Mental health difficulties in children with Autistic Spectrum Disorder (ASD) are common. There is evidence that some can be successfully treated with psychological interventions however few specialist services are available. This evaluation explored parents experiences of a specialist ASD mental health intervention service located within a broader Neurodevelopmental and Social Communication Disorders Team.

Method: Forty-nine parents of children with ASD who had received psychological intervention between 2006 and 2010, agreed to take part in a telephone based survey.

Results: High levels of satisfaction with the service were reported. When discussing the benefits of a specialist service, parents reported that psychologists had ASD-specific knowledge and experience, and were able to provide more targeted intervention. Parents also reported on aspects of the therapy that they found most useful. Suggestions for improvement related to: availability and accessibility, qualified versus trainee psychologists, follow-up and transfer procedures, and ASD appropriate materials.

Conclusion: Suggested areas for improvement generated recommendations for service planning and development. Limitations of the current evaluation are discussed and should be considered when conducting future evaluations.

1 Introduction

1.1 Autism spectrum disorders and comorbid mental health disorders

Autism spectrum disorders (ASD) are characterised by deficits in social interaction and communication, as well as the presence of stereotyped behaviour and restricted interests (American Psychiatric Association, 2000). ASDs have an early onset, lifelong persistence and high levels of associated impairment. Research suggests that individuals with ASD are significantly more likely to present with a comorbid mental health disorder than the general population. For example, a recent meta-analysis found that nearly 40% of children and adolescents with ASD were estimated to have clinically elevated levels of anxiety or at least one anxiety disorder (Van Steensel, Bogels, & Perrin, 2011), compared to 2.4% in the typically developing population (Costello et al., 2003). Increased rates of depression (Leyfer et al., 2006) and disruptive disorders (Simonoff et al., 2008) have also been reported. Comorbid mental health problems in this population are likely to cause additional social and developmental impairment, above and beyond the impairment caused by the core difficulties associated with ASD (e.g., Kim, Szatmari, Bryson, Streiner, & Wilson, 2000).

1.2 Psychological interventions for children and adolescents with ASD

A number of case studies and more recently randomised clinical control trials (RCTs) have been published, indicating that Cognitive Behaviour Therapy (CBT) can be successfully used to treat anxiety disorders (e.g., Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2011; Chalfant, Rapee, & Caroll, 2006; Wood et al., 2009) and anger difficulties (Sofronoff, Attwood, Hinton, & Leven, 2007) in this population. Several authors outline how CBT can be modified and individualised for the cognitive and emotional profiles of individuals with ASD (e.g., Attwood, 2004; Moree & Davis, 2009, Anderson & Morris, 2006; Ozsivadjian & Knott, 2011). Modifications include,

for example, an increased emphasis on affective education, the use of concrete and visual information, and the involvement of a family member or key worker as co-therapist in an attempt to improve the generalisation of skills.

1.3 Service evaluation in child and adolescent mental health services

It is now well established that there is a need to obtain the views of service users of child and adolescent mental health services (CAMHS Outcome Research Consortium, 2008). The importance of service user involvement in service planning, delivery, and evaluation, is highlighted in documents such as the *National service framework for children, young people and maternity services* (Department of Health, 2005) and *Every child matters* (HM Government, 2003). The assessment of parents' perceptions and satisfaction in particular has been viewed as an important method for the evaluation of child and adolescent services (e.g., Stallard, 2001). Parents often play an integral part of the treatment process and their attitudes are critical to engagement and continuation of treatment and are also likely to be important for outcome of treatment (Rey et al., 1999; Bjorngaard, Andersson, Ose, & Hanssen Bauer, 2008). Exploring and addressing parental dissatisfaction with services could therefore prevent premature termination of therapy and improve outcomes for children and their families. Overall, it may facilitate the development of services that are more effective and acceptable to service users (Rey et al., 1999).

1.4 Service user satisfaction with mental health services for children and adolescents

Numerous studies have explored the perceptions and satisfaction of young people and their parents with child and adolescent mental health services. Parents and teenagers have expressed views regarding the ideal therapist, including an empathetic and non-judgemental approach, flexibility, and a feeling of being listened to (Hart, Saunders, & Thomas, 2005). Higher parent satisfaction has been associated with lower caregiver strain at service entry, increased number of sessions, and improvement in youth-reported functional impairments (Garland, Haine, & Lewczyk Boxmeyer, 2007). Rey et al. (1999) found satisfaction scores increased with the number of outpatient sessions and a small but significant correlation between clinicians' rating of outcome and parental satisfaction. Parent satisfaction has also been found to relate to improved mental health outcomes as indicated by interviewer-rated functioning, parent reports of overall problem behaviour, and parent reports of delinquent or aggressive behaviour (Noser & Bickman, 2000).

1.5 Parent satisfaction with services for children with ASD

A wide range of biological, educational, and behavioural interventions are accessed by parents of children with ASD. Overall, relatively high levels of parental satisfaction and perceptions of efficacy have been found for these services (e.g., Goin-Kochel, Mackintoch, & Myers, 2009; Thomas, Morrissey, & McLaurin, 2007) and for specialist neurodevelopmental and ASD assessment services (Giannoulis, Beresford, Davis, Baird & Sclare, 2004; Hackett, Shaikh & Theordosiou, 2009). However, some research suggests that parents of children with ASD are less satisfied with primary care services than parents of children with other disabilities (Liptak et al., 2006) and experience more problems when accessing needed speciality care (Krauss, Gulley, Sciegaj, & Wells,

2003). One study measured awareness and uptake in the 6 months preceding specialist support services in a sample of 64 mothers of children with ASD, in the United Kingdom (Bromely, Hare, Davison, and Emerson, 2004). In relation to clinical psychology services, 97% of mothers reported that they were aware of this service, however, only 19% of mothers said that they had received this service in the last 6 months. The National Autistic Society's (NAS) report, *You Need to Know* (NAS, 2010), evaluated access and satisfaction with children's mental health services nationally within the UK and concluded that the mental health needs of children with ASD are often unmet because of difficulty accessing services locally and/or a lack of specialist ASD expertise. The report captured parents' concerns about lack of understanding of autism and poor ability to communicate leading to ineffective treatment of mental health needs. The report also highlighted parent concerns with the transition to adult services and the importance of parent and school involvement in treatment.

1.6 Service context

The Neurodevelopmental and Social Communication Disorders Team is a national and specialist neurodisability service. Children referred to the service undergo a half-day multidisciplinary assessment procedure, including a discussion of the results with the family. In some cases, families do not have further appointments with the Team and are referred back to local services. However, in many cases, further liaison or interventions are required. The service sees children with a broad range of often overlapping neurodevelopmental problems, including ASD, Attention Deficit Hyperactivity Disorder (ADHD), and Tourette syndrome, but the majority have difficulties on the autistic spectrum as either a primary or secondary diagnosis.

Several years ago a service evaluation was conducted to explore, among other areas, parents' experiences of attending assessment clinics held by the Team (Giannoulis et al., 2004). This study indicated a significant need for post-diagnostic services, such as school liaison, behaviour management, or therapy for emotional difficulties. As a result, a specialist ASD mental health intervention service was established within the broader service with a view to providing intervention post diagnosis to address the emotional and behavioural needs of children with ASD.

The specialist ASD mental health intervention service has been operating within the broader Neurodevelopmental and Social Communication Disorders Team for approximately eight years. The predominant models of intervention used include CBT and behaviour therapy, targeting mostly problems of mood, anxiety and self-esteem, and associated behaviour problems. More severe and enduring mental health problems, such as psychosis or bipolar disorder, are managed in conjunction with the hospital liaison psychiatrist and local Child and Adolescent Mental Health Services (CAMHS). The majority of cases are seen as a result of referral for a full multi-disciplinary team diagnostic assessment, but increasingly direct referrals for specialist therapy are being received for clients with an already established diagnosis. As most people travel a significant distance to the clinic, few people are seen on a weekly basis. Instead, two weekly or three weekly is the norm allowing for more families to be seen, yet with reasonable regularity to ensure treatment progress. A limit is not set as to how many sessions a family are allocated, although families are initially informed that between 6 to 12 sessions is typical. Sessions are usually terminated by mutual agreement with a gradual reduction of sessions and a follow up session three or four months post-treatment. Parents and children are given the choice as to whether they would like to be

seen together or separately. The majority of sessions are conducted with the child and one parent present by mutual agreement.

1.7 Aims of current evaluation

In addition to overall satisfaction, parents' views on the following areas were a particular focus of the study:

1) Accessibility of the service
2) The appropriateness of the type and amount of intervention offered
3) The nature and degree of parent involvement
4) Actual improvement and treatment effectiveness
5) Comparison to previous treatments received, if any
6) Whether there was any advantage to being seen by a specialist service
7) Most useful aspects of therapy and areas for improvement

2 Method

2.1 Participants

Sixty-two potential participants were identified from existing records held by the Neurodevelopmental and Social Communication Disorders Team as having had therapeutic interventions by psychologists on the team from March 2006 to March 2010. Children who had comorbid diagnoses such as ADHD and Tourette syndrome were included, but the primary diagnosis was required to be ASD. Of those identified, 13 did not complete the survey either because they could not be contacted or because they chose to opt-out of the study (see Table 1). The final sample included 49 parents of children with ASD or features of ASD, who had therapeutic interventions from a psychologist between March 2006 and March 2010.

Table 1

Recruitment of sample

	Number of Participants
Unable to contact	6 (10%)
Opt-out in writing	2 (3%)
Opt-out on telephone	5 (8%)
Participated in survey	49 (79%)

Ninety-six percent of respondents were mothers and 4% fathers. Of the child recipients of intervention, 24 (49%) had a diagnosis of Asperger syndrome; 12 (25%) Autistic Spectrum Disorder; 7 (14%) Autism and; 6 (12%) were identified as having features of ASD. Children's ages ranged from 7 to 18 years at the time of intervention, with a mean age of 13 years (SD = 2.9). Forty-four (90%) were male. Some parents (11; 22%) reported that their child's therapy was still ongoing at the time of the interview and one

parent (2%) said that he/she continued to have telephone contact with the therapist. However for the majority of parents (37; 76%), their child's therapy had finished. Seventeen parents (35%) were referred directly for therapy whereas 32 (65%) received therapy as a result of an assessment at the Neurodevelopmental and Social Communication Disorders Team.

2.2 Measure

A semi-structured interview schedule was developed (see Appendix 1) specifically for this study through a literature review of existing satisfaction surveys, and consultation with a qualified clinical psychologist. Items were chosen to address the specific concerns of the organisation and using criteria of clarity, utility and brevity. The interview schedule comprised of forty items including: 21 five-point Likert scale items ranging from 0 to 5; seven questions requiring a "yes" or "no" response; four questions with a choice of responses; and eight open ended questions. Space for additional comments was provided for each area of satisfaction assessed. The interview included open-ended questions to offer parents the opportunity to raise novel topics and to express dissatisfaction (Perreault & Leichner, 1993).

2.3 Procedure

Approval to complete the study was gained from the Guys and St Thomas' NHS Foundation Trust Clinical Governance Department (approval reference: 1704). Participants identified from existing records were sent the following: a covering letter inviting them to participate, a participant information sheet, an opt-out consent form, a self-addressed envelope to return their opt-out consent, and finally, example Likert rating scales for participants to refer to during interview (see Appendices 2 to 5). An opt-out procedure was used and participants were asked to reply if they did not wish to

complete a structured interview over the telephone. If this form was not returned within two weeks, the anonymous demographic information on page one of the structured interview schedule (see Appendix 1) was completed using information from the child's file. The interviewer (principal researcher or research assistant) then contacted the parent and gave the parent a further opportunity to ask questions and decline to participate. Unless parents declined to participate, the interview was carried out either at that time, or at another time convenient for the parent. Questions were read to the parent over the phone and responses recorded on the interview schedule. Responses to open ended questions were recorded verbatim by the interviewer.

2.4 Analysis

Anonymised data was entered into SPSS. Quantitative data, including Likert-scale responses or responses to closed questions, was analysed descriptively and is reported as frequencies. If parents made comments in response to closed questions, these are reported when relevant. A simple content analysis technique (described by Payne, 1999) was used to analyse open-ended questions.

3 Results

3.1 Satisfaction

Parents were asked how satisfied they were with the therapy their child received overall. Most parents reported that, overall, they were “very satisfied” (33; 67%) or “satisfied” (11; 22%) with the therapy that their child received. One parent (2%) said that they were “dissatisfied” and four parents (8%) said that they were neither “satisfied nor dissatisfied”. Most parents (44; 90%) reported that they would “definitely” recommend the service to other parents of children with ASD. Four parents (8%) said they would “probably” recommend the service and one parent (2%) said that they were “not sure” if they would recommend the service. In addition to overall satisfaction, parents were asked how satisfied they were with various aspects of the service which are reported below.

3.1.1 Target areas chosen for therapy

Primary and secondary aims and goals for therapy, as identified from clinical records, are reported in Table 2. Most parents (32; 65%) reported that the main target areas for therapy were chosen by a combination of themselves, the therapist and their child. Twelve parents (25%) said that they chose the target areas for therapy, 4 parents (8%) said that the therapist chose the target areas and 1 parent (2%) said that their child chose the target areas. Almost all parents (48; 98%) were happy with how the target areas were chosen. One parent (2%) indicated that they were not happy and stated that they felt: “the visit was brief so I don't believe full understanding was taken”.

Table 2

Primary and secondary aims and goals for therapy

	Primary	*Secondary*
Anxiety	23 (47%)	8 (16%)
Anger	4 (8%)	2 (4%)
Depression/Low Mood	4 (8%)	3 (6%)
Challenging Behaviour	12 (25%)	5 (10%)
Low Self-esteem	3 (6%)	1 (2%)
Social Relationships	2 (4%)	0 (0%)
Managing Emotions	1 (2%)	0 (0%)
None	0 (0%)	30 (62%)

3.1.2 Accessibility of the service

Table 3 reports data related to parents' satisfaction with the accessibility of the service including: how quickly they were seen for therapy, convenience of appointments with the therapist, availability of the therapist outside of the session time, and location/accessibility of the service. Dissatisfaction figures reflect the considerable distance some parents had to travel to reach the service.

Table 3

Satisfaction with accessibility of the service

	Very dissatisfied	*Dissatisfied*	*Neither satisfied nor dissatisfied*	*Satisfied*	*Very Satisfied*
Quickly	0 (0%)	0 (0%)	3 (6%)	7 (14%)	39 (80%)
Convenience	0 (0%)	1 (2%)	1 (2%)	10 (20%)	37 (76%)
Availability [a]	0 (0%)	1 (2%)	1 (2%)	14 (29%)	27 (55%)
Location/Accessibility	1 (2%)	3 (6%)	5 (10%)	18 (37%)	22 (45%)

[a]Six parents (12%) reported that they had never needed to contact the therapist between sessions

3.1.3 Type and amount of intervention

Five parents (10%) said that they saw a trainee clinical psychologist, 40 (82%) said that they had seen a qualified clinical psychologist and 4 (8%) said that they had seen both a trainee and a qualified clinical psychologist. The majority of parents (32; 65%) told us that their child received cognitive behaviour therapy (see Table 4).

Table 4

Type of therapy received

	% of parents
Cognitive Behaviour Therapy	32 (65%)
Behaviour Therapy	6 (12%)
Other	6 (12%)
Don't Know	5 (10%)

The majority of parents were either "satisfied" or "very satisfied" with the frequency, duration, and number of sessions provided (see Table 5). Number of therapy sessions ranged from 2 to 33 (mean = 9; SD = 7.0).

Table 5

Parental satisfaction with frequency, duration and number of sessions

	Very Dissatisfied	*Dissatisfied*	*Neither Satisfied nor dissatisfied*	*Satisfied*	*Very Satisfied*
Frequency	0 (0%)	3 (6%)	0 (0%)	17 (35%)	29 (59%)
Duration[a]	0 (0%)	0 (0%)	2 (4%)	17 (35%)	29 (59%)
Number[b]	0 (0%)	3 (6%)	1 (2%)	19 (39%)	25 (51%)

[a]One parent (2%) said they did not feel able to answer this because the intervention was carried out with the school

[b]One parent (2%) said that they were unable to answer this question because therapy was ongoing

3.1.4 School liaison

Approximately half of the parents (25; 51%) reported that they had a school visit or a school liaison.

3.1.5 Nature and degree of parent involvement

Most parents told us that they or their partner participated in the therapy sessions (46; 94%) and that their child was given the opportunity to see the therapist by themselves (41; 84%). Most parents found these experiences helpful or very helpful (see Table 6). For those parents, who said that their child was not given an opportunity to see the therapist on their own (8; 16%), six said that it had not been appropriate or necessary and two indicated that they would have liked for their child to have seen the therapist on their own.

Table 6

Helpfulness of school visit/liaison, parent participation in therapy and opportunity for child to see therapist on their own

	Very Unhelpful	*Somewhat Helpful*	*Neither helpful nor unhelpful*	*Somewhat Helpful*	*Very Helpful*
School Visit/Liaison	0 (0%)	0 (0%)	3 (12%)	5 (20%)	17 (68%)
Parent Participation	0 (0%)	0 (0%)	1 (2%)	6 (13%)	39 (85%)
Opportunity for Child to see Therapist on their Own[a]	0 (0%)	0 (0%)	8 (20%)	12 (29%)	17 (41%)

[a]4 parents (10%) said that their child was given the opportunity to see the therapist on their own but this was not taken up

Most parents said that they were "satisfied" (9; 18%) or "very satisfied" (36; 76%) with the degree of involvement they had in therapy. Two parents (4%) said that they were "neither satisfied nor dissatisfied" and one parent (2%) said that they were "dissatisfied" with the degree of involvement they had in therapy, stating that they were given feedback about the therapy but had no involvement in the therapy.

When asked, to what degree contact with the therapist helped them to feel able to support their child in carrying through with strategies in between session, most parents said that the contact "helped very much" (33; 67%) or "helped somewhat" (12; 25%). Two parents (4%) said that it "neither helped nor hindered". One parent (2%) said that it "hindered much more than helped", stating that some of the things the therapist suggested "just weren't possible". One parent (2%) felt that this question was not applicable to them.

3.1.6 Therapist skills and behaviour

Most parents said that they were "satisfied" or "very satisfied" that the therapist: listened to their concerns, understood their child's difficulties, and was able to establish a good relationship with their child (see Table 7). One parent who indicated that he/she was dissatisfied with the therapist's ability to establish a good relationship with their child commented that, the child: did not attend therapy, was not consulted, and was not involved in creating strategies.

Table 7

Parental satisfaction with therapist skills in listening, understanding and establishing relationship

	Very Dissatisfied	*Dissatisfied*	*Neither Satisfied nor dissatisfied*	*Satisfied*	*Very Satisfied*
Listening	0 (0%)	0 (0%)	0 (0%)	9 (18%)	40 (82%)
Understanding	0 (0%)	1 (2%)	1 (2%)	9 (18%)	38 (78%)
Relationship[a]	0 (0%)	1 (2%)	4 (8%)	10 (20%)	32 (65%)

[a]Two parents (4%) indicated that this question was not applicable to them

3.1.7 Actual improvement and treatment effectiveness

Two parents (4%) said that the aims and goals of therapy were "not met", 2 (4%) said that they were "neither met nor unmet", 19 (39%) said that they were "met to some extent"; 19 (39%) said that they were "mostly met", and 7 (14%) said that they were "completely met". Most parents said the intervention was "effective" (14; 29%) or "very effective" (22; 45%), but 12 parents (24%) indicated that the intervention was ineffective. One parent's (2%) response to this question is missing. For those parents that indicated that treatment was not altogether effective nor goals met, comments

included that: therapy was still ongoing, their child was "a bit resistant", "the issue still springs up between treatments", and therapy "tackled fears but not rigidity".

3.2 Comparison to other treatments

Just under half of the parents (23; 47%) reported that their child had received therapy in the past: 74% from local services and 26% by a private therapist. Of these, most parents said that the current therapy was "very much better" (16; 70%) or "somewhat better" (6; 26%) than the other therapy received. One parent (4%) said that there was "no difference". No parent reported that it was worse.

3.2.1 Advantages to being seen by specialist service

Almost all parents (47; 96%) said that there was an advantage to being seen by a specialist ASD service over a generic paediatric service (for example, CAMHS or a child development centre). Parents were asked to report what the advantages were, responses were examined and three main themes were identified: ASD-specific knowledge, experience, and understanding; ASD-specific intervention; and access to other staff groups. Some parents made comments related to more than one theme.

Theme 1: ASD-specific knowledge, experience and understanding

Thirty-four parents (69%) indicated they believed that an advantage of seeing a specialist service was the therapist's knowledge, experience, and understanding of ASD. Comments included "it's somebody who has a real understanding of a child who has complex social communication disorder and to know how this impacts on their ability to function in an everyday context" and "recognising where the child is at and their particular ability and inability to process information and reasoning". Other parents said "you don't feel like you are having to make your case all the time because they know

where you are coming from"; "because nothing was a surprise to [the therapist], she understood all the fears"; and "when we spoke to the therapist she knew what we were saying, made you feel a bit more normal".

Theme 2: ASD-specific intervention

Six parents (12%) indicated that effective intervention was an advantage to a specialist service, for example, "helpful to work with someone who knew exactly the function of the behaviour and how to deal with them" and "recommending activities and behaviours that work in line with their autism and not against it".

Theme 3: Co-ordinated access to other staff groups

Five parents (10%) commented that having other staff groups on site was an advantage, for example, "the whole team is on site so you don't have to traipse around".

3.3 Most useful aspects of therapy

Parents were asked if they could tell us what, if anything, was the most useful aspect of therapy. Their responses were analysed and nine main themes were identified: improving child and parent understanding and awareness; strategies and techniques; support; being understood; an opportunity to talk; responsiveness and availability; school liaison; therapist knowledge, expertise, and/or experience; and finally, parent and/or family involvement.

Theme 1: Improving child and parent understanding and awareness

Ten parents (20%) indicated that one of the most useful aspects of therapy was an improvement in understanding. Comments included "getting a better understanding of my son's behaviour"; "made my daughter more aware of areas she needs to be careful

of and work on…and it's made me more aware of how you can support her in that"; and "perhaps giving us more insight into how to deal with it…it can be frightening not knowing what's going on inside your child's mind".

Theme 2: Strategies and techniques

Twelve parents (24%) indicated that being given strategies and solutions was one of the most useful aspects of therapy, for example, "learning techniques how to deal with his panics"; "being able to have a simple method to be able to explain to [the child] very simple emotions"; "different techniques we tried, each was successful to a degree"; and "Gave me another skill in the tool kit - thinking in a CBT way for that specific phobia. I went on to use it in other areas".

Theme 3: Support

Eight parents (16%) indicated that support was one of the most useful aspects of therapy, for example, "support from [therapist] with my husband and I", "knowing as a family that support is there at the end of the phone", and "the hands on nature of the support".

Theme 4: Being understood

Six parents (12%) indicated that being understood was one of the most useful aspects of therapy, for example, "having someone listen to you that actually understands…so it was the first time that someone understands and believes you".

Theme 5: An opportunity to talk

Six parents (12%) indicated that one of the most useful aspects of therapy was an opportunity for them and/or their child to talk. Comments included "being somewhere

that you and your child can freely speak"; "having someone to talk to, somebody independent and objective"; and "talking through problems with the therapist".

Theme 6: Responsiveness and availability

Six parents (12%) indicated that the therapist's responsiveness and availability was one the most useful aspects of therapy, for example, "I can email and they get back very quickly, incredibly efficient and responsive" and "knowing as a family that support is there at the end of the phone".

Theme 7: School liaison

Six parents (12%) indicated that school liaison was one of the most useful aspects of therapy. Comments included "helping me with [child] through school"; "[therapist] offered school different strategies that have really helped"; and "Psychologist has a very good relationship with school - it has made a big difference".

Theme 8: Therapist knowledge, expertise and/or experience

Four parents (8%) indicated that the therapist's knowledge, expertise, and/or experience were some of the most useful aspects of therapy, for example, "her [therapist] deep and wide experience with this type of child with such complex learning, developmental and ASD issues".

Theme 9: Parent and/or family involvement

Five parents (10%) indicated that parent and/or family involvement was one of the most useful aspects of therapy, for example, "supporting the family and siblings" and "gave me a lot more confidence because I was becoming too manipulated…me learning to take control".

3.4 Suggested areas for improvement

Parents were asked if they could suggest anything that could be improved about the service or anything that could be done differently. Ten parents (20%) said that they could not tell us anything that could be improved or differently, but of those suggestions that were made, several themes were identified.

Theme 1: Wanting more to be available

Eleven parents (22%) indicated that they wanted more of the service to be available, including number and frequency of sessions and more psychologists in general. Comments included "if they could make more of you" and "I wish there was more of it and that more people could access it more routinely".

Theme 2: Accessibility

Four parents (8%) of parents made comments and suggestions related to the accessibility of the service, for example, "I would think a lot of people are denied the help we had", "[GP] having trouble getting PCT to access service", and "suspect that not enough people have access to specialist help".

Theme 3: Location of the service

Four parents (8%) commented on the location of the service. Comments included "only if you could move them closer to us" and "this service should be available in my area or closer…it's money to get to London"

Theme 4: Follow-up or review sessions

Four parents (8%) indicated that they would have liked follow-up or review sessions. One parent commented: "there needs to be a follow-up with the individual with ASD – both the parent and the child".

Theme 5: ASD and/or age appropriate materials

Three parents (6%) indicated that there should be more ASD and/or age appropriate materials, such as information leaflets, questionnaires, and worksheets.

Theme 6: School Liaison

Three parents (6%) indicated that they would have liked more school liaison.

Theme 7: Qualified psychologist versus trainee psychologist

Three parents (6%) indicated that they would have liked to have more involvement from a qualified psychologist in addition to or instead of working with a trainee psychologist.

Theme 8: Transfer to other services on discharge

Two parents (4%) indicated that they would have liked better transfer processes at discharge. One parent said "when [the child] turned 18 he was left and wasn't referred over to the adult service" and the other said "when…sessions end you should be…transferred onto CAMHS as a matter of course".

Other suggestions

The following suggestions were made by only one parent each: more parking, better timekeeping (i.e., sessions not to run over time), more structure to sessions, and a less institutional environment.

4 Discussion

4.1 Summary of results

The results indicate that parental satisfaction with the service was high. Parents were largely satisfied with the frequency, duration and number of sessions, their own involvement with the therapy process, and the provision of school liaison. Most parents were satisfied that the therapist helped them to support their child in carrying through with strategies between sessions, listened to their concerns, understood their child's difficulties, and was able to establish a good relationship with their child. The majority of parents said that the aims and goals of therapy were met to some degree and that the intervention was effective. Parents also identified a number of advantages to being seen by a specialist ASD service including ASD-specific knowledge, experience, and understanding; ASD-specific interventions; and co-ordinated access to other staff groups. Finally, parents reported on the most useful aspects of therapy. In terms of suggested improvements, many parents wanted more of the service to be available and expressed some dissatisfaction with the accessibility and location of the service. Some parents indicated that they would have liked: to see a qualified psychologist rather than a trainee, follow-up or review sessions, better transfer processes on discharge, ASD and/or age appropriate reading materials and resources, and more school liaison.

4.2 Implications of findings

Given the high response rate, these results are encouraging and reflect the majority of parents' experiences for the specific time period. To a degree, the high level of satisfaction is expected given that working within a specialist service naturally leads clinicians to develop expertise in delivering targeted interventions for specific problems and client groups. However, the study also aimed to determine the specific advantages in attending a specialist clinic for intervention and found that parents valued the

knowledge, expertise, and understanding of specialist clinicians. For some parents this meant that they did not have to explain the disorder or the idiosyncratic nature of their child's difficulties and that ASD-targeted interventions were quickly developed. This is consistent with the *You Need to Know* report (NAS, 2010), which identified particular problems such as poor communication and misdiagnosis arising from a lack of understanding of autism in the system. Also consistent with this report, the current evaluation highlights the importance of involving parents in the therapy process and close liaison with schools and other systems.

For the purpose of improving the service, the study also aimed to elicit areas of parental dissatisfaction. Many comments related to the lack of ASD-specific provision locally and hence the need to travel to London for treatment. A previous service evaluation considered whether intervention was feasible at a distance (Giannoulis et al., 2004). The current study has demonstrated that many parents are willing to travel to access an intervention service but that this arrangement is not entirely satisfactory for parents and alternative ways of meeting local needs must be found. Another concern expressed by some parents in this study and by parents and professions in the *You Need to Know* report (NAS, 2010) related to the transition to adult services. Although there is little longitudinal data on mental health needs in autism, prevalence rates in children and adults alike suggest that despite effective interventions, some problems are enduring or may re-emerge at critical stages of life (Davis et al., 2011). Facilitating smooth transitions between child and adults services should clearly be a priority for services.

4.3 Possible areas for improvement

A number of areas for improvement were identified. These related to: follow-up/review sessions, accessibility, identification of suitable cases for trainees, developing ASD specific and age appropriate resources, and transfer processes on discharge.

Formalising follow-up processes

Some parents felt that a follow up or review session would have been useful. It may be helpful to develop guidelines to formalise follow-up and review processes within the service. This may involve, offering a standard follow-up appointment one month or three months after the final therapy session. Parents may also appreciate being provided with a telephone number and contact name which they can use if issues arise after the end of therapy.

Accessibility

Several parents identified that they felt the service was not accessible for some parents and that referrers, including GPs and paediatricians, did not seem aware of the service. It may be beneficial for the service to review referral criteria and pathways to ensure their clarity and to build stronger links with GPs and other referral sources. In order to better meet local needs, the service could also consider providing regional hubs from where outreach or satellite clinics could be undertaken and/or to provide training and supervision for local centres.

Developing ASD and/or age appropriate materials

Several parents felt that it would have been useful to have access to informational materials (e.g., leaflets, questionnaires, and worksheets) that were ASD and age appropriate. It may be helpful to set up a working group to identify relevant materials

and to create a resource base, accessible to all clinicians so that the delivering of materials is standardised within the service.

Identification of suitable cases for trainee

Several parents identified that they would have liked more involvement from a qualified psychologist in addition to or instead of a trainee psychologist. It may be useful for team psychologists to develop guidelines to assist in determining cases suitable for trainees. It may also be useful to determine whether trainee placements should continue to be offered as a first year general child placement or restricted to third year specialist placements. Another option may be to offer more joint working with both qualified clinician and trainee, as this seemed more acceptable to some parents in this study.

Transfer processes on discharge

Several parents indicated that they would have liked better transfer processes at discharge. It may be helpful for team psychologists to develop guidance on transfer processes on discharge, specifically around the time when children turn 18 years of age and/or require ongoing mental health intervention. Early referral prior to the end of therapy may streamline and ensure success of transfer processes. It may also be helpful to develop a list of local support options for parents and/or details about local mental health services, to be provided to all parents and young people on discharge. Developing better relationships with both local CAMHS and Community Adult Mental Health Teams (CMHT) may also assist in this process.

Therapeutic process issues

Several parents made comments related to the therapeutic process (e.g., session structure, time keeping). It may be helpful for team members to consider this feedback

when implementing therapy in the future and if appropriate explore these issues further within the context of reflective practice or supervision.

Organisational Issues

Some suggestions and comments were made in relation to the organisations' environment and parking. It may be most useful to pass these concerns onto the relevant administrative managers to action as appropriate. An inclusion of available parking options in the local area, with the first appointment letter, may also be helpful.

4.4 Impact of the evaluation

As a result of the evaluation, several developments are in progress within the service. In order to address parental concerns regarding accessibility, better links with referrers will be forged with clear referral criteria and pathways. A training day for mental health practitioners was developed and delivered on three occasions in 2011. Further training days have been planned as well as the possibility of follow-up supervision groups. In order to facilitate smoother transition to adult services, a professional has been identified within the team to develop a liaison role between children's and adult services, including the identification of further education, social services, and voluntary sector support services that are available in specific localities. Procedures have been put in place to ensure standard organisational practices are being followed, such as good time keeping, routine offering of school visit/liaisons, and follow-up appointments post intervention. A resource "library" of ASD-specific material has been collated, including literature for siblings of children with ASD. This evaluation also highlighted the need for systematic measurement of outcomes, using parent and child measures as appropriate and behavioural methods such as frequencies and intensity ratings of challenging behaviours. There is now consistent collection and evaluation of parent

outcome measures across psychologists, including objective measures and behavioural observations.

4.5 Limitations of the evaluation

There are several limitations in the current evaluation including issues related to the study's methodology and design as well as the omission of data related to outcome, youth perspective, and socioeconomic information. One design issue relates to the cross-sectional nature of the evaluation. The results of a one-off survey may not compare to the results of continuing assessment of satisfaction (Rey et al., 1999). It has been suggested that parent satisfaction and dissatisfaction information, both quantitative and qualitative, be collected periodically throughout and following intervention programs (e.g., Stallard, 2001).

Although the response rate for the study was excellent (79%), there is evidence that levels of dissatisfaction are higher among non-responders (Stallard, 1995). Those who declined to take part may have done so because they had a negative experience of the service. Furthermore, the sample is derived from parents that volunteered to participate and may be missing parents who did not have the energy or time to complete the survey; perhaps reflecting neediness of their child and unsuccessful intervention (Thomas et al., 2007). However, in order to balance a desire to obtain feedback from parents with respect for their privacy, excessive intrusions (e.g., follow-up letters, repeated telephone calls) were avoided.

While a telephone survey methodology may have resulted in a high response rate, it may have meant that parents felt obligated to provide acquiescent responses (McNaughton, 1994). Motivation to participate in the study may have also resulted from

their appreciation of the services received. In particular, for those families for which therapy was ongoing at the time of the interview, parental responses may have been influenced by a desire for the therapy to continue. For these reasons, it is possible that the positive feedback provided may have an artificial component. One advantage of this study is the inclusion of open-ended questions. It has been argued that specific negative experiences are more likely to be reported in qualitative studies (Avis, Bond, & Arthur, 1997).

The current evaluation lacked the inclusion of multiple sources and measures of effectiveness. It evaluated treatment effectiveness using only two items (parent perceptions of effectiveness and parent perceptions of goal attainment). These items did not measure parent perceptions of outcome related to specific symptoms, such as improvement in mood or behaviour. Parent ratings are highly subjective and depend on the parents' judgments about what constitutes an acceptable degree of change (Goin-Kochel et al., 2009). Asking about effectiveness in general may be especially misleading when used with parents of children with ASD because some parents may rate effectiveness with regard to core autism symptoms (e.g., improved social skills, improved communication). It is true that psychological interventions may affect a range of symptoms and areas of functioning, however, the current interviews did not allow insight into which features the parents were referring to when answering items related to goal attainment and effectiveness. Formal measures were available in some cases, however, they are not reported here partly because measures varied according to treatment problem and clinician preference. In 27 cases, outcome measures were not available because they were not administered, or because measures were not appropriate to the problem, not completed by the family or therapy had not yet concluded. In two cases, only observational behavioural measures were used (e.g., frequency of hitting

behaviour). Parent ratings should be respected as important information which has implications for service development however they should not accepted as an objective indicator of therapeutic effectiveness (Garland et al., 2007; Goin-Kochel et al., 2009).

This study focused on the views of parents and did not capture child and adolescent experiences of the service. Some studies have found that young people are less satisfied with psychiatric services than their parents or carers (e.g., Barber, Tischler, & Healy, 2006). It has also been argued that parents and children have different mental health needs and perceive patient satisfaction in different ways and it cannot be assumed that parents represent their children when quality of psychiatric care is assessed (Biering, 2010).

Another omission from this evaluation is the collection of ethnicity or socioeconomic characteristics. For this reason, we are unsure whether the sample was representative of either those accessing the service or the general population, with regard to these characteristics. It may be possible that the current sample was under-representative of lower income parents and of ethnic minority parents. These socioeconomic factors could have influenced a parent's perceptions of, and satisfaction with the service. Collection of this data may have given further knowledge about the satisfaction of varying service user groups. For instance, previous research has found children with ASD of minority race and ethnicity have been found to receive services at a later age and receive a different mix of services (Mandell, Listerus, Levy, & Pinto-Martin, 2002; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). Thomas et al. (2007) argue that it is crucial that racial and ethnic minority families' perceptions of, attitudes toward, and experiences within the system of care for ASD are articulated and related to levels of service use.

Future evaluations of the service may like to address these limitations, through routine and periodic collection of service user feedback, collection of data related to socioeconomic variables, inclusion of multiple measures of effectiveness relating to specific target symptoms, and inclusion of instruments designed capture the experiences of children and adolescents.

4.6 Conclusions

Overall, the evaluation provided useful information on parental satisfaction with the service. In addition, suggested areas for improvement have led to recommendations for service planning and development.

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6 Appendices

Appendix 1: Semi-structured Interview Schedule

(The following information is to be obtained from the child's file prior to the interview)

Child's details	
Sex	M F
Date of birth	
Date of clinic appointments (number of sessions)	
Main diagnosis / diagnoses (including mental health diagnosis e.g., depression)	
Aims/goals for therapy	
Is the child in care?	No Yes (please specify)

Parent / guardian's details	
Participant identification number	
Relationship to child	Mother Father Guardian Other (specify):
Date of telephone interview	
Comments	

Introduction

I would like to ask you some questions about your experiences of attending the mental health service provided by the Neurodevelopmental and Social Communication Disorders Team at the Newcomen Centre. Some of the questions are open-ended and others give you some options for responding. You should have received a page of seven example response scales, which you may find useful to refer to when answering some of the questions. It should take no longer than half an hour to complete. Do you have any questions before we start?

Presenting Problems

1) What were the main target areas for intervention?

Open

2) a. Were these main target areas chose by (circle one):

1 You	2 Therapist	3 Child	4 Combination

b. Were you happy with this?

1 Yes	2 No

c. If not, why not?

Accessibility of the Service

3) Were you referred as a result of an assessment at the neurodevelopmental and Social Communication Disorders Team or were you referred directly for therapy (e.g., via GP)?

1 Referred as a result of assessment here	2 Referred directly for therapy

4) How satisfied were you with how quickly you were seen for therapy (not assessment)?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

5) How satisfied were you with the convenience of appointments with the therapist?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

6) How satisfied were you with the availability of the therapist outside of the session time?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

7) How satisfied were you with the location/accessibility of the service?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

Comments:

Type and Amount of Intervention

8) Did you see a qualified psychologist or trainee? (circle one)

Trainee	Qualified Psychologist

9) i. What sort of therapy was it?

Open

ii. (if not known) Was it:

1 Cognitive behavioural therapy	2 Behavioural therapy	3 Family therapy	4 Other	5 Don't know

10) How satisfied were you with the frequency of sessions?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

11) How satisfied were you with the duration of the sessions?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

12) How satisfied were you with the number of sessions provided?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

13) Did you have a school visit or school liaison?

1 Yes	2 No

14) If so, how helpful was this?

1 Very unhelpful	2 Somewhat unhelpful	3 Neither helpful nor unhelpful	4 Somewhat helpful	5 Very helpful

Comments:

Nature and Degree of Family/Parent/Carer/Relative Work

15) a) Did you and/or your partner participate in any of the therapy sessions?

1 Yes	2 No

b) If yes, how helpful was this?

1 Very unhelpful	2 Somewhat unhelpful	3 Neither helpful nor unhelpful	4 Somewhat helpful	5 Very helpful

16) a) Was your child given the opportunity to see the therapist by themselves?

1 Yes	2 No

b) If yes, how helpful was this?

1 Very unhelpful	2 Somewhat unhelpful	3 Neither helpful nor unhelpful	4 Somewhat helpful	5 Very helpful

c) If no, why not? Would you have liked them to?

17) How satisfied were you with the degree of involvement you had in the therapy?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

18) To what degree did contact with the therapist help you to feel able to support your child in carrying through with strategies in between sessions?

1 Hindered much more than helped	2 Hindered slightly	3 Neither helped nor hindered	4 Helped somewhat	5 Helped very much

Comments:

Therapist Skills and Behaviour

19) How satisfied were you with how the therapist listened to your concerns?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

20) How satisfied were you that the therapist understood your child's difficulties?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

21) How satisfied were you that the therapist established a good relationship with your child?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

Comments:

Actual Improvement and Treatment Effectiveness

22) To what extent do you feel the aims and goals of therapy were met?

1 Not met at all	2 Met to some extent	3 Neither met nor unmet	4 Mostly met	5 Completely met

23) Overall, to what degree do you believe the intervention was effective?

1 Very ineffective	2 Ineffective	3 Neither effective nor ineffective	4 Effective	5 Very effective

Comments:

Comparison to Other Treatments

24) Has your child received any other therapy in the past?

1 Yes	2 No

25) If so, what was it?

Open

26) How do you think the current therapy compared to other therapy received?

1 Much worse	2 Somewhat worse	3 No difference	4 Somewhat better	5 Very much better

Comments:

Overall Satisfaction

27) Overall, how satisfied were you with the therapy your child received?

1 Very dissatisfied	2 Dissatisfied	3 Neither satisfied nor dissatisfied	4 Satisfied	5 Very satisfied

28) Would you recommend this service to other parents of children with Autistic Spectrum Disorder?

1 No, definitely not	2 No, probably not	3 Not sure	4 Yes, probably	5 Yes, definitely

29) Was there an advantage to being seen by a specialist ASD service over a generic paediatric service? (eg CAMHS, child development centre)

1 Yes	2 No

a. If so, what?

Open

30) Can you tell us what, if anything, was the most useful aspect of the therapy?

Open

31) Can you tell us anything that could be improved about the service or anything that could be done differently?

Open

32) Would you like an opportunity to talk with another member of the team?

1 Yes	2 No

Comments:

Thank you very much for taking part in this study. You are welcome to contact me if you have any queries. My number is 020 71889372.

Appendix 2: Cover Letter

Guy's and St Thomas' Hospital NHS
NHS Trust

Newcomen Centre
Tel: 020 7188 4624
E-mail: cara.kingston@gstt.nhs.uk

Guy's Hospital
St. Thomas' Street
London SE1 9RT
Tel: 020 7188 7188

20 August 2010

Dear Parent,

You may remember that you and/or your child recently attended at least one appointment with a psychologist on the Neurodevelopmental and Social Communication Disorders Team at the Newcomen Centre, Guy's hospital. We are writing to all parents who have had appointments for psychological interventions between 2006 and 2010 to ask them to take part in a survey we are carrying out.

Our survey aims to find out about families' experiences of attending the service and to find out if they have any suggestions for improvements. The survey will involve completing an interview over the telephone sometime between August and October this year. This should take no more than half an hour.

I have enclosed a sheet outlining more information about the survey and an example response choice sheet that you may find useful during the telephone interview. I have also enclosed an opt-out form should you not want to participate in the study.

We would like to take this opportunity to thank you for considering taking part. Please feel free to contact Cara Kingston on 020 7188 4624 if you have any comments or questions.

Cara Kingston
Clinical Psychologist in Training

Dr Ann Ozsivadjian
Child Clinical Psychologist

Appendix 3: Participant Information Sheet

Participant information sheet

You are being invited to take part in a service evaluation study that has been approved by the Guy's and St. Thomas' Clinical Governance Department. Before you decide if you would like to take part, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information.

We are keen to find out about families' experiences of mental health intervention services for children with Autism Spectrum Disorder provided by psychologists on the Neurodevelopmental and Social Communication Disorders Team. We want to learn more about how you found the experience and we are also interested to know about any suggestions you have for improvements. We are inviting the parents of all children who attended the service between 2006 and 2010 to take part in the study. The results of the study will be fed back to the team and will be available to parents on request. Similar studies carried out in the past have provided us with useful feedback and have led to changes in how we work.

If you agree to take part in this study, we would like to ask you complete a short telephone interview at a time that is convenient for you. The interview will involve questions about your experiences of the service and will also provide an opportunity for you to make comments or suggestions. The interview will last between fifteen minutes and half an hour and I will write down your answers.

It is up to you to decide whether or not to take part. If you do, you will still be free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your child's care in any way.

The information you provide will not be presented in a way that will allow either your child or yourself to be identified. The information you provide will be treated in confidence and in accordance with the law.

Although not of direct benefit to your own child's care, the information provided will be useful in improving the service we offer to families in the future.

This study is being carried out by a Clinical Psychologist in Training as part of the requirements of a Doctorate in Clinical Psychologist. The trainee will receive supervision from a Chartered Clinical Psychologist during the study.

We are going to contact a parent of every child who has had an appointment unless they tell us that that they would not like to be contacted. Therefore, if you would NOT like to be contacted to take part in this study, please complete the enclosed form and return it to Cara Kingston, Newcomen Centre, Guys Hospital, Great Maze Pond, London SE1 9RT within 2 weeks.

If you have any questions or concerns about the project, please do not hesitate to contact Cara Kingston on 020 7188 4624.

Thank you for taking the time to consider participating in this study.

Cara Kingston
Clinical Psychologist in Training

Dr Ann Ozsivadjian
Child Clinical Psychologist

Appendix 4: Opt-out Consent Form

Guy's and St Thomas' Hospital NHS
NHS Trust

Study Number: 1704
Participant Identification Number:

Opt-out form

Title of Project: Families' experiences of mental health intervention services for children with Autistic Spectrum Disorder provided by psychologists on the Neurodevelopmental and Social Communication Disorders Team

Name of Researchers: Cara Kingston and Dr Ann Ozsivadjian

*Please read and fill in the details below if you would **not** like to take part in this study.*

I would **NOT** like to be contacted to take part in the study about families' experiences of attending appointments for psychological interventions.

Name: _____

Child's name: _____

Date: _____

Please send this completed form to Cara Kingston, Newcomen Centre, Guys Hospital, Great Maze Pond, London SE1 9RT if you would **not** like to take part in this study.

Thank you very much.

Appendix 5: Example Likert Rating Scales

Below are some example response choices for some of the interview questions. If you choose to participate in the telephone survey, you may find it useful to have these to refer to during the interview. Don't worry if you can't find them at the time though, or would prefer simply to listen, the interviewer will remind you of the choices!

1.

1	2	3	4	5
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied

2.

1	2	3	4	5
Very unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Very helpful

3.

1	2	3	4	5
Hindered much more than helped	Hindered slightly	Neither helped nor hindered	Helped somewhat	Helped very much

4.

1	2	3	4	5
Not met at all	Met to some extent	Neither met nor unmet	Mostly met	Completely met

5.

1	2	3	4	5
Very ineffective	Ineffective	Neither effective nor ineffective	Effective	Very effective

6.

1	2	3	4	5
Much worse	Somewhat worse	No difference	Somewhat better	Very much better

7.

1	2	3	4	5
No, definitely not	No, probably not	Not sure	Yes, probably	Yes, definitely